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THE IMPORTANCE OF AMBIVALENCE :

CARING FOR PEOPLE WITH LEARNING DISABILITIES

WHO ENGAGE IN SELF INJURIOUS BEHAVIOUR

OPEN UNIVERSITY

SPRING 1997

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THE IMPORTANCE OF AMBIVALENCE

**CARING FOR PEOPLE WITH
LEARNING DISABILITIES WHO ENGAGE IN
SELF INJURIOUS BEHAVIOUR**

THESIS ABSTRACT

THE IMPORTANCE OF AMBIVALENCE :

CARING FOR PEOPLE WITH LEARNING DISABILITIES WHO ENGAGE IN SELF INJURIOUS BEHAVIOUR

THESIS ABSTRACT :

This work addresses the question of how nurses care, on a daily basis for people with learning disabilities who engage in self injurious behaviour. It suggests that the nature of the emotional component of the care work undertaken differs from that which the mainstream literature presents. This difference, it is proposed, lies in the necessary length of the relationship between these carers and their clients and in the intractability of the behaviour - self injury - which forms the focus of nursing care.

The work explores the frameworks which have been used in caring for and 'treating' those with self injurious behaviour in the past and suggests that some of these models resonate through the current care situation. The history of the professional group who constitute the research participants- nurses for people with learning disabilities - also forms a theme in the consideration of where current defence mechanisms may have originated.

A grounded theory approach was taken to illuminate the defences which may be in play in this difficult care situation. Carers from two residential health service homes participated in the study, all of whom have continuing contact with people with learning disabilities and self injurious

behaviour. The participant group constituted : nineteen registered nurses for people with learning disabilities; two registered general nurses; and eighteen care assistants. Their ages ranged from nineteen to mid-fifties and their care experience from a few weeks to over twenty years.

The data from the first round of unstructured interviews, which asked the question, " How do you feel about your work with people who self injure?" was analysed to form the themes for a second, semi - structured round of interviews. The transcribed data was analysed by means of coding, constant comparison and memoing, which enabled the emergence of central categories. These were organised into : emotional reactions; behaviour; and belief systems. The analysed data was referred back to the participants following data analysis and after data interpretation for verification.

The interpretation of the analysed data flowed from both the epistemological stance of the researcher and the methods adopted. The work proposes that nurses continue to care for their clients by holding together and holding apart conflicting feelings and beliefs about their clients and their work. This is undertaken in the context of the concept of themselves as carers which they receive from the care environment which includes the professional and historical issues above. The tension which is inherent in this situation is formed by the ambivalence carers feel about their work, their clients and their role and these processes together constitute the process by which nurses continue to care for this needy client group.

CHAPTER ONE

INTRODUCTION

THE MIRRORING OF METHOD AND CONTENT

CHAPTER ONE

INTRODUCTION

THE FOCUS OF THE RESEARCH

This research has sprung from many years of contact with people with learning disabilities whose behaviour challenges services, society and carers. Whilst acknowledging the success of a variety of interventions for some individuals, for others, including those whose care is the focus of this work, many years of professional intervention have done little to provide alternative, less challenging behaviours. Originally, within health service care, these behaviours were viewed from a medical perspective and treated chemically; later viewed from a (largely behavioural) psychological stance they were treated by environmental manipulation; and most recently, they have been viewed as socially caused and treated by a change in the physical and emotional environment of care (Whitehead, 1992). These changes in philosophies of care and the concurrent power struggles of professional groups, have exerted little sway over many self injurious, aggressive or withdrawn individuals whose care raises the central questions in this research.

In this context of change, the people who are the focus of this study - direct care staff - continue to provide day to day care for people with learning disabilities and often many other, complex needs. The client group for whom the research participants care engage in a wide range of behaviours which are currently deemed 'challenging', self-injury being one of the most prevalent behaviours which care staff witness on an hour - to - hour, day - to - day basis. This contact raises the central question of the research : how do nurses care on a continuous basis for people whose behaviour seems to indicate such distress with the world and the self and which is so distressing to witness? What are the protective and coping mechanisms which carers employ to maintain their own humanity and to continue to recognise that of people who are persistently destructive and violent to themselves and sometimes to others? This work asks carers those questions and through processes of sensitive listening, of analysis, reiteration, reanalysis and interpretation, indicates means of supporting carers and, consequently, improving services for people with learning disabilities who engage in self injurious behaviour.

In many ways the progress of the research mirrors the history of care for this group: The institution, coupled with a medical model approach to care appeared to offer straightforward ways of helping people with their problem of self injury : containment/asylum, diagnosis, treatment and cure. As this simplistic approach proved inadequate in view of people's problems and inappropriate in the light of their needs and rights, more complex care and treatment vistas have opened until we reach the current situation of multi-modal, facility independent care services (Whitehead, 1992). In a parallel fashion, the research was originally envisaged as a reasonably ordered and linear process which would yield results and provide answers. The issues here, too, have become more complex and have required much more sophisticated means to address the problems raised.

THE ORGANISATION OF THE THESIS

The thesis is split into six sections : the work, however, is and has been a whole, with each part influencing the others. Thus, the compartmentalising of issues into chapters gives the reader a retrospective sense of order and security. Such ordering is necessary for both writer and reader to begin to clarify and understand the issues. This introductory chapter serves three purposes. The first of these is to explore the roots of the research. In light of the obvious emotional disease and suffering of the individuals who engage in self injurious behaviour, it may appear rather perverse to focus questions around the emotions of carers. However, I feel that an understanding of the emotional world created by carers is essential in supporting them to care : hence the focus of the work. As part of this process, another aim of the chapter is to clear the emotional ground : that is, to set out my personal answers to the research question and in doing so, to start the process of illustrating my relationship to the research question, the research data and its analysis. The chapter also begins the process of exploring the research approach taken, and also exploring the importance of reflexivity in nursing and in the research process. The final purpose of this chapter is to sketch in for the reader some of the themes which will be central to the work and to flag up some of the theoretical perspectives which shape it.

The second chapter presents an account of the concept of self injurious behaviour and professionals' attempts to understand, interpret and control individuals and their dis-ease. The broader philosophies and models which have provided the impetus and direction for change form a framework for this exploration. This chapter aims to present a context - historical and contemporary - for the work ethos within which the research participants care for people with learning disabilities who self injure. It also provides the necessary background for an understanding of the third chapter, which broaches many questions about the nature and basis of knowing in nursing.

The history of the profession has a profound impact on the way in which knowledge is both acquired and evaluated, and the relationship between 'how we know' and 'how we do' is a crucial one in any profession. Chapter three presents a brief overview of the roots of nursing/care for people with learning disabilities and highlights how this evolution differs from the popular version of 'general' nursing's emergence. This leads into discussion of the move away from a 'totality paradigm' (Parse, Coyne and Smith, 1985) as the foundation for knowing in nursing and nursing's attempts at self definition. Issues around care and caring, as central to the 'business' of nursing form the focus of the latter part of the chapter reviewing the literature on the importance and cost of caring. As with the totality of the research itself, both this chapter and that which precedes it, move from a position of relative clarity and certainty to arenas within which much less is 'given' and many more complexities appear to vie for attention.

These areas raise, and go some way towards answering, questions around the choice of research methodology, which is the subject of chapter four. This chapter outlines and defends the particular approach taken to the work, with reference to broader material - outside the nursing literature - on qualitative methodologies. Reflection forms a major theme in current nursing practice and the reflective processes of the research undertaken mirror this. Issues of the role/place of the researcher in the work are discussed in this chapter. The research process itself is described and discussed in relation to the whole question of rigour in qualitative work.

Chapters five and six present the research analysis and interpretation. The research data has been presented in chapter five in the form of the emotional themes which emerged from the work. These themes have been grouped according to my perception of the research participants' perception of their feelings about their work. As such, the themes are largely titled by participants' own phrases and extracts from the interview data form a crucial part of this section of the work. These extracts are illustrative of the feelings which the particular theme explores and as such demonstrate for the reader the relationship between the more abstract presentation of the theme and the 'real world'. The themes enable the reader to see a way through a mass of collected data, and prepare the ground for the interpretation which follows in chapter six. The final section of the work offers the theory which has emerged from the data. It draws out from the carers' experiences a common means by which nurses have enabled themselves to continue to care for self injurious individuals. The status of the theory poses an interesting question which is addressed in this final chapter as are issues of the implications, both practical and theoretical, of the work.

THE REFLECTIVE NATURE OF THE WORK:

The notion of reflection is one which is used increasingly within nursing - the nurse of the 90s is a "reflective practitioner" (Schon, 1983). This piece of research is founded upon reflection. I recognise that this interpretation of the stories of carers is necessarily my account of the world created by the research participants and by me. The concept of reality as 'out there' and, consequently, the researcher as some kind of conduit for it, is now recognised by some as naive. (Schwandt, 1994, in Denzin and Lincoln, (eds.)) So too is the idea that the qualitative researcher can report the participants' view of the world, whilst somehow disappearing into the

narrative (Van Maanen, 1988). These issues will be explored in chapter four, but it is important that my epistemological stance is clear from the outset and thus two of the most important questions will be considered here.

The more obvious, and perhaps the thornier of these, is the question of the validity of the research. Whilst the fundamental shift of world view (discussed in chapter three) would render inappropriate the use of means appropriate to evaluate quantitative research, the rigour of the piece needs to be demonstrated. Unlike quantitative, and what Denzin and Lincoln (1994) refer to as the traditional and the modernist phase in qualitative work, this evaluation cannot be attempted post-writing - by merely holding some kind of frame to the piece and examining the fit. The constant dialogue between researcher and material, interpretative and field processes require continuing reflection which then facilitates judgements of academic and methodological rigour.

A more important reason for the reflective nature of the text is my emerging awareness that the separation of 'that-which- is known- via-the-research' and the 'process of research' is, in fact, an illusory one. The themes which emerge in this piece of work as central to the research participants' experience - ambivalence and tension - are those which characterise the research work. That these two facets of the research, the knowing and the known, are parallel processes has been emerging slowly in the literature around qualitative methodology. Van Maanen (1988) traces it through style - realist, confessional and interpretist - and Denzin and Lincoln (1994) through five moments in the evolution of qualitative research. The place of the researcher in the research (in the field, the interpretation, analysis and writing) is the focus of this theoretical work. That the two are inseparable has led to the centrality of reflection within qualitative work.

Schwandt (in Denzin and Lincoln, 1994, p. 125) states, " knowledge and truth are created, not discovered, by mind". It might appear that the adoption of this line of thought will lead to the swamp of solipsism, but reflexivity - exposing to question how it is that one knows - opens up new approaches in the rigour of evaluating qualitative research.

PERSONAL REACTIONS

With this in mind, I return the focus to the topic of the research. Although each behaviour which might be considered to be challenging brings its own stressors to carers, the particular difficulties of caring for people who engage in self injury are to be the focus of this research. Self injury in people with learning disabilities is an intractable problem, as the clinical literature will reveal, but the task of attempting to reduce the frequency and intensity of the behaviour presents only part of the complex care situation faced by, in this case, nurses. The nurse not only has to assist the client in managing his or her emotion and behaviour, but also has to form a reliable emotional world of his/her own in an extraordinarily stressful and unpredictable environment. What are my own experiences of managing these processes?

I will begin with the self injurious act. The emotions I experience when witnessing another human being deliberately harming him/herself vary according to the extent of the damage inflicted and the level of intention which I perceive in the other's action. This question of the self injurer's awareness of, and intention in, his/her action is one which I feel is crucial in my own reaction to the behaviour, and yet difficult to justify. The underlying emotions of horror, fear, desperate sadness and anger enter into my reactions to all such incidents in degrees which vary according to the two judgements above. Somehow, if I feel that the person is out of control in some way and, therefore, is not aware of the behaviour then the emotional urgency is removed,

although the physical urgency to control the behaviour remains. If I can thus view the behaviour as unintentional, it seems to lose some of the perceived desperation, and to elicit more sadness and pity than despair and anger. The more controlled the self injury appears, the more complex is my emotional reaction to it.

This, I think, stems from my inability to conceive of the desire to inflict pain upon myself. This apparently rather naive statement should be put in the context of viewing the overt and crude self injury of many learning disabled people as part of the range of self injury we see all around us. Clearly, along the continuum of mental health/ill health, many engage in self injury to a greater or lesser extent, from suicides through to minor but persistent self - injurers. Most adults would admit to some behaviours which are directly harmful to the body - smoking, drinking alcohol, eating a diet at times less than healthy - which can blend into addictions and eating disorders almost unnoticed. The scope for emotional self harm is even greater : those who engage in destructive relationships; those who 'set themselves up' to fail; and institutionally fostered and rewarded guilt. These intensely sophisticated and complex self injuries are not those which are engaged in by the learning disabled people who are the ultimate concern of this research. I am concerned with people who bang their heads, either with their fists or on objects, who bite themselves, who damage ears and eyes, who scratch their skin. It is this crude self injury which I cannot imagine committing.

Thus if the self injury I witness appears to be a behaviour chosen from a variety of other possible behaviours in a given situation and the aim of the behaviour is, purely, to harm oneself, I find it hard to make any emotional sense of this behaviour. The concept of empathy is one which currently receives much attention within nursing, although, as Kristjansdottir (1992) points out, it is a concept which is not clearly defined or understood within the profession. However,

all of the literature suggests an understanding of the other's emotional life. This question of the congruence between our assumptions about others' emotional lives and their experience of them is an issue which requires further attention. For example, in undertaking this research in which I ask nurses to share some aspects of their emotional lives with me, we have a shared language, similar socialisation and educational processes and the ability to ask, 'Is this what you were saying to me..?' In attempting to enter into the emotional world of people with limited communication skills, who have spent many years in institutions, we fall back on best guesses and our knowledge of the individual to understand their emotional lives. With so few, and such gross indicators of another's feelings, can we possibly draw any useful parallels between our own emotions and those of our clients? Where is the basis for empathy? These issues are crucial in our consideration of care and as such, I will return to them in chapter three. This also highlights another theme of the work : that my personal reactions to the research process and content - will recur throughout the 'script'. I feel that the epistemological stance adopted renders these reactions a crucial part of the overall work.

EMOTIONAL HEALTH

The other strand, to remain with the theme of emotion, which seems important to me in working with people who can challenge us, is that of ensuring one's own emotional health. In the past, nurses have been placed in an emotional dilemma : whilst doing a job which is centrally concerned with caring, they were expected not to be emotionally engaged with their patients and clients. This image of the kindly but distant nurse is one which is fading within the profession, to be replaced by a nurse who can engage emotionally (Aldridge, 1994). The ability to feel with the client (empathy) and to value one's own emotional reactions is a skill which is

fostered within nurse education (Kirby and Slevin, 1992). The ability to convey warmth, understanding, caring is valued highly, but what of the negative emotions a nurse may feel toward a patient or client? The whole issue of balance for the nurse and his/her emotional well being forms the focus of this study. Chapter three will address the concept of care and empathy and illustrates that the institutional defences so clearly identified by Menzies (1960) may have shifted, but that the need for protection is strong within the professional carer.

The literature on self injury reveals that this group of learning disabled people are at much greater risk of physical abuse from carers than those who do not self injure (Rusch, Hall and Griffin, cited in Emerson, 1990). As a profession we need to acknowledge feelings of frustration, anger and resentment as much as positive emotions, and learn to handle these constructively. Certainly, feelings of anger on my part nearly always occur when working with self injurious people, and I have always sought ways to discharge this anger harmlessly, rather than direct it at the client, myself, or an unsuspecting member of my family.

An echo of the uninvolved professional has also been reflected in earlier approaches to qualitative research, where the researcher was expected to form a rapport with the research participants, but not to allow emotion to interfere with the supposed detachment of the reported work (Kleinman and Copp, 1993). Increasingly, this approach is recognised as a misrepresentation and the processes of engagement become part of the knowing/known in themselves. For example, in this work many of the participants are known to me - some for many years : further, these people share with me a bond of common professional socialisation and of 'tacit knowledge' (Ely et al. 1991). "What matters more than our degree of identification is what we do with our feeling" (Kleinman and Copp, 1993, p. 45).

PROFESSIONAL FRAMEWORKS :

These socialisation processes also feed into our emotional reactions to caring for self injurious people. Although within research, the traditional reliance on what Parse et al.(1985) call the totality paradigm is being challenged by different world views, within practice the need to predict and control is still strong. In the late 1970s and early 1980s nurse researchers began to reject a reductionist view of human beings as a "sum of their biological, psychological, social and spiritual parts" (Nagle and Mitchell, 1991, p. 21) and to adopt methods which attempt to capture the reality of the individual or group. However, nurses in practice still use a reductionist approach in delivering care. The nursing process consists of : assessing a client/situation; planning care; implementing/managing the implementation of care; evaluating the care given. Thus, we are still predicting and controlling, which necessarily demands an authoritative approach (see Smith, 1991).

Self injury is behaviour which it is notoriously difficult to diminish or change : within the framework of the nursing process, this intractability will be viewed as failure, adding to carers' frustration. In many ways this also mirrors the particular research process. Both were originally conceived having a distinct beginning and a distinct end. However, in working with self injurious people, one does not stop collecting data/ assessing and one rarely sees an endpoint at which to evaluate. Similarly, with the research, where does one stop the dialogue, the interplay of data and interpretation? Caring for the learning disabled person who self injures and undertaking qualitative research both invoke processes which necessarily involve the self and an awareness of the role of self in the work.

The problems raised by the intractability of the behaviour are exacerbated by the 'mixed economy of care' which demands that professional carers should be able to demonstrate skills and achieve results. The future of the nurse for people with learning disabilities is constantly under threat and many within the profession argue that in order to survive, nurses need to specialise in the care of the most needy groups, i.e. profoundly and multiply disabled people, the elderly learning disabled and those who engage in challenging behaviour (Kay, Rose and Turnbull, 1995). If this is to be a successful strategy for professional survival, then a paradigm shift may be necessary. As I have noted above, many of the difficulties experienced by people within these groups and those caring for them are not amenable to interventions which 'repair' the situation either in the medium or longer term. Thus, to work within a care delivery system which presupposes 'successful' intervention to solve perceived problems may be inappropriate. The adoption of a role other than 'fixer' may be more meaningful for both the client and the nurse in this situation. These are difficult issues to which I will return in later chapters.

Another strand which I can identify in my own reaction to dealing with self injurious behaviour is that I feel the client is rejecting many of the values which are important to me. One of the cornerstones of care practice for nurses for people with learning disabilities is Social Role Valorisation through which a society, (and in many care services this has been interpreted as carers) enhances the competencies of people with disabilities and, consequently, their image (Wolfensberger, 1983). People with learning disabilities have the same value, needs and rights as other citizens and care is offered on this basis. Nurses attempt to provide valued opportunities and promote valued behaviours and to demonstrate care and respect for individuals. Yet the behaviour of deliberately harming oneself seems to be a denial of our attempts to promote value and self worth and a rejection of care. Maintaining high standards

of care and interaction with the persistent self injurer can be trying, and calls for high levels of insight and good emotional management strategies on the part of the carer. The question of whether the continuing reliance on Social Role Valorisation (with greater or lesser adherence to its origins) as the ideology to shape and direct services for people with learning disabilities is appropriate, is tackled in chapter two and revisited in chapter six. The use - misuse and abuse - of Social Role Valorisation principles have in practice, I would suggest, led to a shortfall not just in services for the most needy but also in the preparation and support of their carers.

CONTINUING CARE?

In undertaking this research I was continually touched by the warmth, affection and care shown by the nurses to the learning disabled people with whom they were involved. Much of the narrative I heard from individual nurses was concerned with the strengths/abilities/skills of a particular individual which could be appreciated once you got to know that person. In the face of (sometimes) gruelling working conditions, being with people who can be aggressive, dealing for much of the day with the routine and (sometimes) unpleasant mundanities of living, these nurses cared - despite the apparent lack of communication on the part of the client group and the lack of support the carers received.

The question of how nurses achieve this is the basis of the research. We do, despite the difficulties outlined earlier, "explain" behaviours to ourselves to avoid being thrown into a state of inertia by that which the actor is unable to explain to us. We can and do rationalise and intellectualise others' suffering and we do distance ourselves from our own emotional reactions to others' pain. What would the options be? My assumption is that the relationship we

have with the other is intense and difficult and that the defence mechanisms we use contain and limit the emotional costs of 'caring'. Nurses caring for the self injurious are not paralysed by the suffering they see around them, nor are they excessively pessimistic or depressed by their work with people who can be challenging. How does each carer enable him/herself to work in a meaningful and constructive way? What is the process that individuals begin and sustain to maintain their own emotional integrity?

One way to answer these questions is to ask them of those who care for people with learning disabilities and self injurious behaviour on a daily basis. The process of uncovering individuals' emotional strategies is one which involves a high level of disclosure and, therefore, trust. I feel that I am assisted in establishing an appropriate emotional environment through my professional background. I am a nurse for people with learning disabilities and spent some years caring for people with challenging behaviours : thus I am familiar with the culture and accepted as an 'insider'. I feel that this quality will give me more access to the emotions of the nurses who participate in the study as we have a common work background and, for the qualified nurses, a shared professional socialisation. Ely (from Ely et al., 1991) suggests that one aim of the research process is to render the familiar unfamiliar, and my closeness to and familiarity with the research environment and issues may have had a negative impact on the work. However, the importance of reflection in the whole process goes some way toward addressing this issue, as does the validating of my thoughts and ideas with people both inside and outside that world.

The process of finding answers to the questions posed will involve at least two strands : for the reader the finished text must render the unfamiliar familiar; for the writer, the process must render the familiar unfamiliar (Ely et al., 1991). A host of questions cluster around these issues : does my relationship with the participants mean they will be more or less honest with me? Do they feel the research is worthwhile or are they doing me a favour? How did my feelings for them colour the known? Similar issues plague the qualitative researcher (Schwandt, 1994, Ely et al., 1991, Hunt, 1989) and by exposing and reflecting upon them, their impact on the work may be gauged. I will return to these issues in chapter four.

One issue of central importance to the research is the difficult nature of the work undertaken by the research participants and I do not want my familiarity with it to rob it of its grave and distressing quality. The psychodynamic stance adopted in the interpretation of the data recognises this complex and emotionally harrowing situation. This way of knowing is one which is relatively new in the field of learning disability (Sinason, 1992) and one which, as it deals essentially with the conscious and unconscious emotional life, can offer much to those whose emotional lives may be largely unexpressed or communicated in an idiosyncratic fashion.

The complexity of the carer/cared for relationship will form the basis of the final section of the work, but a preliminary skirmish into the field shows it to be fraught with problems. The relationships between this client group and the paid carer, must be sculpted and resculpted, often without the use of language, often in an unconscious fashion. Thus, paying attention to those conscious and unconscious tensions within the care dynamic leads me to a psychodynamic interpretation as the most useful. Seen from a psychoanalytic standpoint the violent and self destructive behaviour witnessed by these carers may act as both a physically and an emotionally forceful reminder of these urges toward destruction in all of us. The individual who engages in these behaviours insists upon our viewing and managing these emotions in others. How this is done is the heart of this study.

The approach has a corollary also in the research process. One needs to be aware of one's motivation for the choice of research topic and site. Being alive to transferences and one's reactions to them shapes the course of data collection and interpretation (Hunt, 1989) .

Some insight into the defences employed - particularly in a situation resonant with violence and death - by oneself and others, is crucial.

If this piece of nursing research - nursing being essentially a practice profession - is to have been worthwhile, it must ultimately be of help to those caring for people who engage in self injurious behaviour and consequently to self injurious individuals themselves. By making overt common emotional frameworks and processes involved in care, it may offer nurses more insight into our own and others' coping behaviours and provide a means by which nurses may be enabled to help and support each other. The perceived shift away from a deterministic and parental approach to caring for people with learning disabilities to a relationship based more in sharing and partnership may well herald a change in emphasis in carers' expectations of themselves and make more apparent the need for support in the emotional labour of care.

Within the piece, no claims to 'the truth' are made; no attempt is made to claim the generalisability of the findings made and, as such, the work attracts a particular set of criticisms. Benoliel (1984) suggests that nursing should be open to the possibility of multiple realities, and I would extend this to suggest that as a profession, we must attempt to increase our tolerance of ambiguity and ambivalence. Frameworks which seem to offer certainties - nursing models as bases for individual practice, Social Role Valorisation as a basis for care provision - are very attractive. However, this simplification of the care situation does not tally with the experience of practice. Being, in a positive way, with people who bang their heads and gouge their eyes, has little to do with whether the person uses integrated or segregated leisure facilities : it is about the enormous complexities of shared consciousness. Similarly, the research process itself addresses these same issues of shared awareness and consciousness. It is hoped the end result will shed light on patterns within both of these arenas.

CHAPTER TWO

BEGINNING WITH CERTAINTY

A LITERATURE REVIEW

CHAPTER TWO :

BEGINNING WITH CERTAINTY : A LITERATURE REVIEW

This chapter aims to contextualise the research undertaken in order to give the reader some insight into the care situation - practical, professional and emotional - in which the research participants and those for whom they care find themselves. It is important that the current work is seen as part of a process of evolution rather than as a snapshot and as such the roots of perceptions, of practices and of attitudes need to be explored. The chapter addresses three areas in order to illuminate this development. The importance of recognising the work within a process of change is also reflected in the following chapter where similar issues of origin and growth are broached in relation to the state of knowledge in nursing.

The first area to be explored in this chapter is what self injurious behaviour entails. This may appear to be a matter of common sense yet the provision of a definition and consideration of factors which appear to predispose to self injurious behaviour present difficulties of professional and ideological differences. The second area illustrates this point as the work presents both older 'scientific' and newer 'social' explanations of the behaviour. This review of the literature is fairly lengthy and serves to illustrate the belief systems which have permeated the lives of people with learning disabilities and also have forged the attitudes and behaviours of carers. Thirdly, the way in which carers viewed self injurious behaviour is reflected in this section of the work. Each of the frameworks for viewing self injurious behaviour has necessary

correlates in what carers do for/with people with disabilities and the relationship between the two people. The changes in these relationships are highlighted along with the increasing complexity of the work that carers - many of them unprepared for the role - are asked to undertake.

By beginning with this literature review it is also possible to begin tracing the parallels between the research process and the research findings. In the same way that the research process began from a position of certainty of direction and moved to one of uncertainty, so this chapter illustrates changes in the process of knowing about caring for people with self injurious behaviour. This work illustrates a move from frameworks which suggested - by their basis in 'hard' science - certainties of both the evolution of, and approach to, these behaviours. Later frameworks (both chronologically and in terms of the layout of this chapter) propose more sophisticated means to address difficulties which are increasingly seen as multifactorial and, as such, demanding of a more complex and comprehensive response. Whilst recognising that these approaches overlap and are indeed, often used together, they are considered separately here in order to demonstrate the process of change.

Thus, the chapter begins by discussing the nature and prevalence of self injurious behaviour in the population of people with learning disabilities. Even in this first section, difficulties of boundary setting and of clarity are evident. The next section of the chapter addresses more traditional scientific frameworks for viewing self injurious behaviour - biological/medical explanations and psychological theories. Approaches developed since the move away from 'hard science' as the ideology which underpins care provision for people with learning disabilities are discussed in the last section of the chapter. The issues raised in the introductory chapter are pertinent here. The literature review often presents self injurious behaviour as

something alien and other, engaged in by 'disabled' persons. Reflection of our own propensity for self harm and self destruction whilst it cannot be continuously referred to in the text, should be borne in mind throughout the reading of the material.

DEFINITIONS?

Singh et al. (1981) write, "The study of self-injurious behaviour is replete with definitional problems...." (p. 207) and I feel that in evolving a working definition for this research, these problems need to be acknowledged. The difficulties raised by the differing ideological and epistemological stance of researchers will obviously lead to differences in framing the behaviour. However, a more immediate issue is that many of the definitions used imply some intent in the behaviour, be it to communicate or to cause damage to the person involved. In fact as Maisto, Baumeister and Maisto (1978) point out, in reality we can perceive only the result of the action, not the intention. Further to this, I would suggest that each individual's perception of the behaviour differs and the subsequent difference in understanding and explanation forms a crucial hurdle in undertaking any work with someone who self injures. The question of intention is philosophical rather than semantic, but one which is pertinent here as the assumptions we make concerning others' mental lives often colour our language. This is not to discount the individual's internal world and indeed the perceived meaning of a behaviour must necessarily influence our reaction to it; rather, it points to a need for awareness of the bias one has in interpreting others' behaviour. For each of us, our histories, perceptual set, values base, world view, all influence our understanding of the world. That others share this view is often taken as a working assumption - indeed, this assumption oils the wheels of everyday life. However in this context, awareness of how our own world is filtered through our

consciousness is crucial in acknowledging this imposition of an assumed reality. The theme of constructivism - of how we create the world we inhabit - runs through this piece of research and the impact of personal, philosophical and professional frameworks for viewing the world must be borne in mind throughout this chapter.

One aspect of the definitional problem which needs to be examined is that of the continuum of self-injurious behaviours in people with disabilities. Bachman (1972) writes, "It appears that self injurious behaviour is not suicidal behaviour in that it occurs repeatedly while, if successful, the suicidal response occurs only once. Also, the topography of self injurious behaviour is different from the more common forms of suicidal behaviour..... "(p. 212). Bachman's comment serves to highlight another definitional difficulty. At one end of the continuum of these behaviours, we appear to have those, which, although self injurious, fulfil the criteria for stereotypy. At the other we witness behaviours, which are complex and appear to be goal directed. Lourie (cited in Murphy and Wilson, (eds) 1985) draws attention to the rhythmicity seen in children and its possible link with self injurious behaviour.

Two studies take this finding a stage further : Shintoub and Soularic (cited in Jones, 1982) and DeHissovoy (1961) noted the incidence of self injurious behaviour within normal children. The former study noted that 11% -17% of children aged 9-18 months engaged in self injury. This figure fell to 9% by the age of 2 and the behaviour had disappeared by the age of five. The latter study noted 15.2% of children engage in some form of self injury between the ages of 19 and 32 months. If we accept this suggestion, perhaps we should explore the idea that self injury in some of the population of people with a learning disability may be caused by a failure to develop beyond the developmental age at which these behaviours appear to be surprisingly

common. This concept of individuals 'sticking' at particular stages along which ever domain is under consideration is currently rather an unfashionable one. The reasons for this are clear : suggesting a slowed (or a lack of) development in one domain is easily generalised to the whole person. However, developmental approaches may offer some indicators for support and development for people with learning disabilities if used appropriately.

The attempt to view all of these behaviours through one lens poses problems for any attempted definition, for the researcher and, of particular importance for this piece of work, for the carer. How then are we to define such a broad range of behaviours? Oliver, Murphy and Corbett, in their 1978 survey, define self injurious behaviour as, "Repeated, self-inflicted, non-accidental injury, producing bruising, bleeding or permanent tissue damage." Bachman (1972) writes, "The behaviour of individuals who inflict physical damage and, perhaps, pain upon themselves can be called self injurious behaviour." Phillips and Muzaffer (cited in Bachman, 1972) use the term 'self mutilation' to describe the behaviour under discussion and define this as : "those measures carried out by the individual, upon himself, which tend to cut off, to remove, to maim, to destroy, to render imperfect some part of the body". For the purposes of this literature review I have adopted the ageing (1966), but widely accepted definition of self injurious behaviour, of Baroff and Tate, (cited in Heidorn and Jensen, 1984) : self-injurious behaviour is defined as repetitive acts by individuals directed towards themselves which result in physical harm. This definition avoids the pitfall of inferring intention in the behaviour and also makes the point that this is recurrent behaviour, rather than an isolated incident. The theme of intention in the behaviour is important in the wider context of the research as one of the themes to emerge from the work was, in fact, the carers' need to find meaning, and consequently, intention in the self injurious acts of individuals. This highlights, I feel, one of the important differences in ways of viewing self injury. In much of the literature reviewed, the "behaviour " is approached

separately from the "people who engage in this behaviour" as much of the literature in the field is presented in these terms - an expression, I would suggest of the need for the kind of research being undertaken here. A consideration of people entails emotion and reflection, the need to involve oneself, if only in a limited way; splitting the behaviour from the person removes this threat to the emotional equilibrium of the researcher/ carer. For the carer who needs to make emotional sense of the individual's world, such space between the individual and the behaviour is not afforded.

PREDISPOSING FACTORS

Explanations of self injurious behaviour in people with learning disabilities adopt different foci - environmental, medical, and (rarely) emotional. The need to contain, predict and control people and their behaviour is reflected through the literature and one strand in this approach is the teasing out of variables which people who engage in self injurious behaviour have in common. This again reflects a distancing from the individual's experience of self injurious behaviour. The first of these, the inverse correlation between self injurious behaviour and intelligence quotient has been established in the literature for some years. The huge debate around measured I.Q. and its relevance to disability is illustrative of the point made earlier in relation to the use of 'stage' models. The questions around the validity of I.Q. testing aside, that a figure (a score) could describe the variety and richness of a person represents a gross simplification of individuals' relationships with themselves and their worlds. When used as a predictor for such complex issues as social skills, self care abilities or appropriate residential placement, the tool is being abused. However, if used as one of a number of means to compare people to other people, it can inform the discussion. Berkson and Davenport 1962 (in Ballinger, 1971) seem to be the first writers to draw attention to this relationship between IQ

and self injurious behaviour, which is now an accepted part of the literature, and well supported by other reviews and surveys. Yet detailed explanation of this phenomenon is lacking. Rojahn (1986), Oliver et al. (1987) and, more recently, Emerson (1990) all provide evidence for this inverse correlation, and findings from Ballinger (cited in Murphy and Wilson (eds.) 1985, see Fig. 1, p. 52) suggest that people with an I.Q. of less than 20 are at greatest risk of self injurious behaviour. Much of this literature fails to suggest what the implications of a low, measured I.Q. may be for the individual and his/her experiences of the world, but, if this material is to be useful, this link is surely the next step.

The increased incidence of self injury with other disabilities (Baumeister and Maisto, 1978) would appear to provide evidence for the existence of diffuse and severe brain damage in the potential/actual self injurer, yet more research in this field is needed. Maisto, Baumeister and Maisto, (1978) suggest that the biological factors involved in profound disability imply nervous system, and therefore, sensory damage . However, the link between diffuse/severe brain damage and self injurious behaviour need not be directly causal : the presence of such severe damage will lead to difficulties in many areas, for example mobility, self care and communication. Inability to move around, to make needs known, and to communicate emotion may lead to the onset and maintenance of self injurious behaviour. An example of this is the suggestion, (Oliver and Head, 1990 among others) that self injury is a communicative behaviour used by those who have no other, or limited communication skills, a point to which I will return later in the chapter.

This linking of self injury to brain damage to I. Q. presents a seductively simple scenario. Locating the 'problem' within the disabled individual relieves carers of the possible distress of examining themselves and their role in the causation and maintenance of this the behaviour.

Containing the dis-ease within the individual prevents infection of others. Within the medical and traditional nursing world this location of dis-ease within the individual and its inherent 'other-ness' facilitated the treatment of the patient/client and the distancing of the carer from the dis-ease. Placed firmly within the boundary of the other, the carer's responsibility could be reduced to following a programme of treatment rather than engaging in the other's world. This theme of the acknowledgement and/or rejection of guilt is one which echoes strongly through the research.

PREVALENCE

This leads us to consider the prevalence of self injurious behaviour. Most of the literature, definitional problems aside, places prevalence rates at between 8% and 15% of people with learning disabilities who live in residential care (Murphy and Wilson, 1985, Griffin et al, 1986, Oliver et al, 1987, Maisto et al, 1978). It is more difficult to estimate the number of learning disabled people living in the community (either independently or with their families) who self-injure, but the available literature would point to a figure between 1% and 4% (Carr 1990, Emerson, 1990). The influence of the environment - clearly the issue in question here - is one which is addressed later in this chapter. However, the material in the remainder of this chapter focuses more upon people with learning disabilities who have paid carers, than upon those who live with members of their families of origin, as it is with this group of carers that the research is concerned. The proportion of people for whom the research participants care who engage in self injurious behaviour is even greater than the figure for the 'institutionalised' population generally. As chapter four will illustrate, one of the residential homes used for the study caters specifically for women whose behaviour challenges others. Consequently, the proportion of all challenging behaviours is higher here than in the remainder of the population. The other

research participants work in a home for people with varying degrees of learning disability, all of whom have sensory disabilities and as this chapter has revealed, this may predispose toward self injurious behaviours.

What, then, are the behaviours which are labelled "self-injurious" within this population? The chart below indicates the topography of self injurious behaviours within a client group similar to that for whom the research participants care.

TABLE ONE :

From : Maurice and Trudel : 1982 : Self injurious Behaviour : Prevalence and Relationship to Environmental Events. **In :** Hollis and Meyers : 1982 : Self-Injury (Eds.)

		N	%
Headbanging	-against objects, walls, floors	139	18.6
	-hitting the head with objects, usually in hand		
	-with one part of body, usually hand or fist, sometimes knee		
Hitting the	-against another part of body	126	16.9
body	-against an object		
	-projecting whole body onto floor, wall		
Rubbing a part	-with another part of the body	37	5.0
of the body	-with object		
Scratching	-excessive scratching on part	97	12.5

	of body with nails or fingers		
Pulling hair	-pulling or tearing hair or eyelashes or body hair	31	4.1
Eye gouging	-pushing in the eyes, turning eyes, lids	7	0.9
Biting self		99	13.3
Pica	-eating objects, including coprophagia	38	5.1
Gouging, digging	-pulling out flesh, teeth, nails	73	9.8
Insertion of	-fingers or objects	37	5.0
Masturbation	-excessive	25	3.3
Pinching self -		7	0.9
Other	-ruminating, cutting self, burning self, stopping circulation	34	4.6

This topography is supported by much subsequent work, e.g. Ballinger, 1971, Emerson, 1990. There is some discrepancy with Oliver et al.'s 1987 work. The first difference is that Oliver's work suggests that skin picking and self biting are more common behaviours than head banging. More interestingly, Oliver's paper takes into consideration those people who engage in multiple self injury. There would appear to be a correlation between self injurious behaviour and other behaviours which may be considered to be challenging. Dimzang and Cheatham (1970) note that the display of outward directed verbal and physical aggression may

accompany self injury, while Emerson (1990) suggests that approximately 50% of those who engage in self injury have other challenging behaviours. This includes multiple self injurious behaviours, which appear common, one estimate being 50%-75% (Emerson, 1990). The behaviours represented above are all apparent in the client group for whom the research participants care, in roughly the proportions suggested above. However, the home for people with sensory disabilities does have a higher than expected proportion of people who gouge their eyes - for obvious reasons. A point which it may be worthwhile to bear in mind is that in both of the homes, this behaviour features as one of many challenging behaviours and the carers are dealing with, for instance, aggressive and destructive behaviours as well as self injury.

Thus far, the review has demonstrated that recognising and labelling behaviours as self injurious is not a straightforward task. The environment within which the behavior occurs, the stance of the carer, the dis/abilities of individuals all affect the way in which the behaviour is perceived. The following section of this chapter demonstrates how frameworks for viewing behaviours can shape the lives of learning disabled people who engage in self injurious behaviour and the shape of the care they receive.

FRAMEWORKS : WAYS OF SEEING AND DOING

This part of the chapter reviews the literature on explanations of and subsequent care/treatment approaches to, self injurious behaviour. Whilst obviously not as discrete as presented here, the fact that these frameworks are underpinned in practitioners by a belief set and ideology leads to

some partitioning of therapy. Further, whilst recognising that schools of thought and practice can be incompatible, the value of each can surely be judged only in relation to individuals whose difficulties are approached through them. Just as no school has a monopoly on caring, none has a monopoly on efficacy. Despite the current dominance of Social Role Valorisation as the ideology (albeit often distorted) which underpins services, reliance on these other models, simultaneous (and sometimes incongruently) with Social Role Valorisation continues to pervade service provision and service providers' views. For instance, as an extreme example, one service which is known to me had a philosophy and operational policy based on O'Brien's (1986) service accomplishments, yet contained a seclusion room which was used regularly for one of the clients. The difficulties presented by the adoption of any one model will become apparent as the piece progresses but as this literature review makes clear, the safety offered by these models is hard to relinquish.

This part of the review will, in keeping with the whole work, start with that approach which by necessity of its epistemological framework appears most certain of its ground - a point which will form the basis of reflection in later chapters.

BIOLOGICAL EXPLANATIONS

Within this approach, a range of possibilities for the onset and maintenance of self injurious behaviour arise, from the obvious and direct to the complex and sophisticated. In the former category, one reason suggested for the onset of self injurious behaviour is that of an undiagnosed physical disorder, leading to pain or discomfort. In those people with a profound handicap and/or no means of communication, seen within this context, self injury would seem to be an understandable response to circumstances. Indeed, the screening sequence to explore the motivation for self injurious behaviour designed by Carr (1977) suggests that medical

screening should be the first step. Infections, pains and aches which afflict us all could trigger self injury if relief from pain was difficult to achieve.

At a more sophisticated level, two clinical syndromes exist of which self-injury is a recognised sign : Lesch-Nyhan syndrome and Cornelia de Lange syndrome. Nyhan (cited in Demchak and Halle, 1985) cites an X-linked recessive inborn error of purine metabolism in which hypoxanthine - guanine- phosphoribosyl transferase is either not produced (Cataldo and Harris, 1982) or its activity is diminished (Nyhan, cited in Demchak and Hall, 1985). This leads to an increased level of purine, which is associated with increased uric acid levels. It has been suggested (Hoefnagel, cited in Demchak and Halle, 1985) that the self injury typical of this syndrome is a result of irritation caused by the increase in uric acid. Despite this fairly clear biological cause for the self injury, behavioural treatments have been attempted and an interesting paper by Wurtele, Abby, King and Drabman (1984) presents the results of their and others' studies. Many workers still view this behaviour as having an organic cause, but as being maintained by a learning process. Wurtele et al.'s own study reported the combined use of mouth guard (to prevent tissue damage) and self control procedures which decreased the individual's self biting behaviour dramatically. These results were transferred effectively to the person's home setting.

Discussion on the role of beta endorphin and other neuropeptides in the onset and maintenance of self injurious behaviour feature throughout the biological literature. There appear to be two hypotheses. Firstly, that opiate antagonists may act as a positive reinforcer in self injurious behaviour (Cataldo and Harris 1982 , Richardson and Zaleski, cited in Beckwith, Couk and Schumaker, 1986), and secondly, that these substances may mediate the individual's perception of pain, thus increasing analgesia to the self injurious response (Oliver and Head, 1990).

Attempts to provide support for these hypotheses have produced contradictory results. Work cited in Beckwith et al.'s (1986) text demonstrated that the administration of nalaxone led to a marked reduction of self injurious behaviour. However, an attempted replication of this study by Beckwith failed to show any decrease in the self injury in the individuals he studied.

Emerson (1990) also reports conflicting evidence in the literature from Barrett et al. (1989) and Singh and Millichamp (1985). Oliver and Head (1990) review this literature and extend the arguments of the influence of biochemistry in the onset and maintenance of self injurious behaviour by noting the link between dopaminergic agents and the occurrence of self injury in animals and in people with Lesch-Nyhan syndrome. They report the successful use of dopamine blockers in people with self injury (non Lesch-Nyhan) from Gualtieri et al. (1986 in Oliver and Head, 1990). They further postulate a link between the dopaminergic and opiate systems in the production and maintenance of self injurious behaviour, as other researchers (Smee and Overstreet, Gillam and Sandyk, both cited in Oliver and Head, 1990) have demonstrated that high levels of endorphins can lead to dopamine receptor supersensitivity. Evidently, despite the practical and ethical difficulties and costs of work in this area, further research is needed to clarify the role played by neurochemistry. However, it can provide only one strand among many in addressing such complex issues.

Reduction of an individual's behaviour to a manipulation of chemical levels represents one facet of a world view from which nursing is retreating. Having worked within a care system under sway of the medical model, where behaviours and emotions are routinely pathologised, it would be easy to reject this framework as limited. However, there is scope here for multi professional research, utilising insights from differing world views. As a reflection of this framework for explanation, a proportion of the literature on treatment approaches examines

the use of less specific pharmacological intervention in this behaviour. Lapierre and Reesal (1986) make the positive point that benzodiazepines may be useful where anxiety is a precipitating factor in the engagement in self injury, although the cautions raised more recently about the extended use of these drugs should be heeded. They also make the point that where self injury seems to be some function of epilepsy, then anti-epileptic medication is effective in reducing the behaviour.

Neuroleptic drugs are commonly used in people with learning disabilities for myriad reasons: Oliver and Head (1990) rank pharmacological treatment as among the most common forms of intervention in self injurious behaviour; Lapierre and Reesal (1986) estimate that 40-50% of people in U.S. institutions are treated with psychotropic medication; Maisto, Baumeister and Maisto (1978) report that of their 182 self injurers, 61% were administered "behaviour suppressing drugs"; Oliver, Murphy and Corbett (1987) report 44% of their 596 self injurers receiving psychotropic medication.

Despite the alarmingly high proportion of these clients being given this medication, with their damaging and sometimes permanent side effects, there is little evidence (that presented earlier notwithstanding) of its effectiveness. Aman and Breuning (both cited in Lapierre and Reesal, 1986) suggest that the most commonly used drug, thioridazine, is effective in only 10-15% of "cases". In light of this evidence, why do drugs continue to be given to the self injurious client? Oliver and Head (1990) suggest that medication is used purely as a management strategy - to sedate rather than to treat. The need to "quieten" rather than to approach client needs more constructively, the authors continue, arises from a care situation in which very needy people are cared for by largely untrained staff, within an organisational structure which does not encourage or support more innovative approaches. Working within a medical framework had,

as the next chapter will demonstrate, a huge impact on the work of nurses caring for people with learning disabilities. Nurses did not need individuals skills and abilities as their role was - in terms of care - largely custodial and in terms of 'therapy' - one of following prescribed patterns of drug administration. In managing large numbers of people, not only was the need for the establishment of rapport and relationships absent, neither was the time and space to do so available (see Ryan and Thomas, 1980).

A movement away from medical domination within the realm of care for people with learning disabilities has brought with it a decline in this type of treatment. However, in a culture in which the power of science continues almost unabated and the profit motive remains a driving force the attraction of pharmacological intervention is clear. Having considered some of the questions raised by the adoption of a medical model for viewing self injurious behaviour the discussion will now focus on psychological frameworks : specifically, psychodynamic and behavioural approaches.

PSYCHODYNAMIC APPROACHES

Psychodynamic hypotheses first appeared more than three decades ago within this field, and offer alternative frameworks through which to approach the self injurious individual. Whilst at the care interface, as we saw in the previous section of this chapter, the need to 'do' may militate against the long view of psychoanalytic approaches, it is clear from the literature across disciplines that there is no quick fix for self injurious behaviour. Psychoanalytic frameworks make the opportunity to explore the other's inner world with the person, and thus address the seat of dis-ease. This necessarily involves the carer in exploring his/her own dis-ease in working with someone whose relationship with the self and the world results in self destruction and

consequently raises the difficult and uncomfortable issues which form the focus of this research.

In terms of the developing self, Bychowski (1954 in Carr, 1977) suggest that self injurious behaviour could, for the profoundly handicapped person, provide a means of differentiating self from non-self. Melanie Klein's work, to which I will return, is useful here in drawing a picture of the developing individual's world, and will serve as one means through which we may view the disabled individual's relationships. Other writers, among them Stavrakaki and Klein (1986), suggest that self injury is a form of guilt reduction. The suggestion here is that one's awareness of disability and the total impact this has on others leads to a sense of guilt, displayed through and assuaged by self injury. Based on this explanation, work by Lovaas et al. (cited in Carr, 1977) attempted to use reassurance of worth as a means of assuaging guilt and thus reducing self injury. However, this reassurance appeared to reinforce the self injury and thus aggravated the behaviour.

The focus of these explanations on the emotional meaning of the behaviour displayed has some congruence with the concept of self injury as a communicative behaviour, as discussed below. It assumes a level of insight and emotional development which had previously been discounted on the basis of the individual's perceived disabilities in other domains. Spensley (1984) suggests that it is the understanding of how the world is for the disturbed person which will offer an explanation of why behaviours occur.

In recent years, much pioneering work has been done at the Tavistock Institute, in the use of psychoanalytic psychotherapy with people with learning disabilities. Valerie Sinason's 1992

publication outlines one way in which we may view the concept of behaviours which may be challenging in this client group. She makes a distinction between primary handicap - the original learning disability - and secondary handicap - the defensive use or abuse the individual makes of the primary damage (Sinason, 1992). Opportunist handicap is that which is damaging to the individual, but which acts also as a defence. She suggests that we understand these self injurious behaviours by considering the individual's emotional history, and by making connections between the person's often traumatic experiences of disability and the behaviour presented. She cites much research e.g. Corbett and Freeman, which indicates that the higher incidence of disturbance in the disabled population is not due to brain pathology. Approaching these challenging behaviours as opportunist handicaps, and revealing the emotional trauma which underlies the need to defend the self and others, offers a release from the unacknowledged source of dis-ease for both the disabled person and his/her carers. Sinason reports successful work with people who engage in self injurious behaviours, across a wide range of perceived ability. She argues that it is the inability of carers to receive and to bear the messages which disabled people send which locks us into cycles of self injury and aggression. Recognition and containment of the person's anxiety and fear enables therapeutic change. The acknowledgement and exploration of the other's world when that other carries disability and dis-ease calls for high levels of emotional awareness and articulateness on the part of the carer. This stance is clearly quite different from that outlined above and is affected by the economic and social issues addressed below. This piece of research addresses the very question of how we can continue to engage emotionally with people who have self injurious behaviour in a meaningful way - how can we 'hear' the emotional message of the self injurious person without being consumed by it? The framework for explaining and 'treating' self injurious behaviour which is discussed next does not entail these difficult questions of emotional involvement, as in

its purest form it demands detachment from carers.

ENVIRONMENTAL EXPLANATIONS

Behavioural approaches to viewing behaviour look for cause and maintaining factors in the functional relationship between the individual's behaviour and his/her environment. The allure of 'science' so prevalent in behavioural psychology highlight some of the problems which those who care for people with learning disabilities have in differentiating their professional history from that of general nurses. These issues are of direct relevance to the work undertaken here as it is this professional history which forges the boundaries of knowing in care and thus the shape of this research.

Behavioural approaches, echoing medicine, give the carer something to 'do' for the self injurious individual. As one may administer drugs orally or more dramatically by injection, similarly within the behavioural frame one may reinforce other behaviours or use 'time out'. This approach also, partly because of its link with science, gives an (illusory?) certainty to which carers may cling in a sea of dis-ease and uncertainty.

The issue of the increased prevalence of self injury in people with learning disabilities who live in institutions casts the environment in the role of a predisposing factor. Whilst acknowledging the influence of institutional environments and practices upon the appearance and maintenance of self injury, Emerson (1990) suggests that self injury in itself, places the individual at a greater risk of admission to residential care. Much of the work around care and intervention is premised by the belief that the environment plays a (greater or lesser) role in the causation and maintenance of self injurious behaviours and shifts in social policy and care provision over the last twenty years have acknowledged the importance of environment on the individual's quality

of life and life experiences. However, much of the work cited above explores the occurrence of these behaviours in the 'family' setting; evidently, more sophisticated research than suggested by family/care, home/institution dichotomies is needed. A seminal piece of work in this field is that by Pahl and Quine (1985) which aimed to investigate the stresses in caring for a person with learning disabilities at home. The work shows clearly that having a child with behavioural problems correlates strongly with a high malaise score in parents/carers. Carr's (1990) work examining educational support for the families of people with behavioural/psychiatric disorders has highlighted the need for family support if the stress of caring for a relative is not to lead to requests for care placement. Thus, issues other than environment are clearly implicated in the aetiology of challenging behaviours generally, and self injurious behaviour specifically.

Reinforcement hypotheses suggest that self injurious behaviour is used by individuals as a means of ensuring interaction with others (if I bang my head someone talks to me) or, alternatively, as a means of escape (if I bang my head, I won't have to...) Much of the literature in the field focuses on these suggested causes of self injury and consequently manipulation of the environment to remove the 'pay off' for self injurious behaviour. Edelson, Taubman and Lovaas (1983) report an interesting study in part of which twenty self injurious children were observed for increasing or decreasing engagement in self injurious behaviour prior to or following intervention by staff members. This work provides fairly clear evidence for the relationship between self injury and positive reinforcement. Heidorn and Jensen (1984) suggest that the positive reinforcement hypothesis has received most attention in the literature of all of the theories of motivation of self injurious behaviour and cite a variety of studies, e.g. Bucher and Lovaas, Ferster, and lastly, Repp, Dietz and Dietz, as support. The case study presented by the two authors suggests that in the child studied, positive reinforcement was a strong factor

in the maintenance of the self injurious behaviour. " ...S, when left by himself would scream or engage in self injury until someone talked to him or touched him" (Heidorn and Jensen, 1984). The adoption of a reinforcement approach necessitates the focus of intervention and observation being on specifically targeted behaviours, and thus rules out acknowledgement of the rich and wide variety of influences within any interaction.

Emerson (1990) writes, " It does seem to be the case that much self injury serves important functions for the individual. So, contrary to outward appearance, it should be regarded as adaptive rather than a maladaptive behaviour and may represent an important way in which people with severe impairments can control or communicate about their world" (p. 226). Thus, self injury may be seen in the literature as an escape behaviour. Skinner writing in the 1950s , (Bachman, 1972) proposes two conditions under which self injurious behaviour might be learned, one of which is that, "individuals might expose themselves to aversive stimulation if by doing so they avoid even more aversive consequences"(p. 221). Despite the evidence above, Green (cited in Bachman, 1972) comments on the fact that reports of self injurious behaviour as an avoidance behaviour are difficult to find. He does however comment on the incidences of children who may have been physically abused by parents/carers, who find that self injury is a way of preventing further parental attack. Thus, the approach of others will be seen as aversive, and the individual will seek escape via self injury.

There appears to be more recent evidence to support this hypothesis. Rusch et al. (from Emerson, 1990) report that of a client population in an institutional setting, the group of abused clients had 300% more people with self injurious behaviour than matched control group. Attempting to untangle the complexities of this situation presents difficulties to both the theorist and the practitioner and such a simple explanation clearly does not address the tangle

of emotions inherent within the care dynamic.

Oliver and Head (1990) would appear to support Emerson's reframing of self injurious behaviour as adaptive response. This theme of self injury as adaptive is reflected in the next approach : that of self injury as communication. "The increased severity of learning disabilities and the discrepancy between the receptive and communicative abilities may contribute to the unreliability of an effective expressive communicative repertoire and thus the self injurious behaviour may become the more powerful and reliable behaviour in terms of communication in a limited sense" (Oliver and Head 1990 p. 105). The communication hypothesis is one which has been gaining ground over the past ten years and the interpretation of this hypothesis has become more sophisticated over this period. Initially the self-injurious act is seen as an attempt at communication in the absence of speech or another communication system. The provision of a means of communication-- speech, a signing or symbol system-- will eliminate the need for self injury. Whilst all behaviour may be seen as having a message value, Emerson (1991) questions the value of this re-interpretation. He views the communication hypothesis as, "a metaphor for directing attention to the environmental determinants of challenging behaviours..."(p. 9). Again, one may question the value of this re-interpretation as, witnessed by the review above, awareness of environmental factors is not lacking.

Day et al. (cited in Emerson, 1991) distinguish between perlocutionary behaviours - those, "which influence others, but in which intent can only be inferred"(p.8) - and illocutionary behaviours - "non-verbal behaviours in which communicative intent is clearly obvious."(p.8) The authors argue that self injurious behaviour might be either. Two difficulties arise here. Firstly, there is the whole thorny issue of inferring intention into another's behaviour, particularly if that other does not have a communication system. Secondly, how is one to

distinguish which of these any one piece of behaviour represents? What are the criteria for, "clearly obvious"? In partial reply to the first of these, Durand and Crimmons, (1988) distinguish cognitive intent from functional intent, the former referring to the actor's account of the intent of a communicative act and the latter to the actual behaviour-environment relationship. The difficulties for the former with the particular client group under discussion here are self evident: again, what purpose is served by the re-formulation in the latter? The debate concerning the communication hypothesis does appear to be rather removed from the reality of caring on a day to day basis for people with self injury, however, Bird et al. (1989) report successful amelioration of self injurious behaviour in two clients using a replacement communicative behaviour.

BEHAVIOURAL APPROACHES TO CARE

The manipulation of the relationship between behaviour and consequence appears, from the literature, to present one of the major treatment approaches within the field. The adoption of this technique provides a means to help people who self injure which appears both accessible and inexpensive. The techniques can be broken down into relatively simple steps and instructions, and thus used with the large proportion of the workforce which is unqualified. The difficulties raised by this approach for both client and carer are addressed below.

Much case study work is considered by Bachman (1972), in his classic review of behavioural approaches which highlights the use of positive reinforcement of alternative behaviours as a popular treatment. Differential reinforcement of other behaviours is considered more closely by Lancioni and Hoogeeven (1990) who found that it is ineffective in people with high rates of self

injury. The reason for this is self evident : if an individual's performed behavioural repertoire contains little apart from challenging behaviour, opportunities for differentially reinforcing alternative behaviours are scarce. Further, given the previously discussed high correlation between self injury and other forms of challenging behaviour, one could envisage a situation of having to reinforce the "least challenging" of the behaviours presented. Whilst such accounts of the research present a very clear picture of the efficacy or otherwise of these interventions, issues around the problems for both clients and carers in sustaining 'clinical' contact in extreme circumstances are ignored. Further, Crisp and Coll (1987) cast doubt on the efficacy of this intervention, citing other studies from the 1970s in which differential reinforcement of other behaviours had little or no effect. Nonetheless, successful reductions in self injurious behaviour have been reported using this technique, notably the thorough work by Woodward, Magninn and Johnston (1987).

Differential reinforcement of incompatible behaviours (rewarding behaviours, which make simultaneous engagement in the target behaviour impossible) has been reported as having some success. Crisp and Coll (1985) used this intervention with a client who engaged in high frequency (100 times per minute) head banging. In order to become mobile, the client needed to grasp a walking frame with both hands : this being incompatible with the self injury. This intervention appears to have been extremely successful, as the client's self injury reduced not only during the experimental period, but had not reappeared at an eighteen month follow up.

Jenner (1984) reports impressive results using overcorrection with six children engaging in self injurious/stimulatory behaviours. Unlike other studies, Jenner suggests an abbreviated period of overcorrection which will, he argues, give the learning disabled person the opportunity to "realise the pairing of the target behaviour with the treatment" (p. 176). Clements and Dewey

(1980), demonstrate in their single case study that overcorrection can be an effective means of treatment, but their work highlights two potential difficulties : firstly, that the techniques require a staffing situation in which the client may receive much individual attention; and secondly, that as the target behaviour declines, other challenging behaviours may increase.

PUNISHMENT

The area of debate over the use of punishment is one fraught with difficulties of a moral and ethical nature but this review will focus entirely on the reports of un/successful intervention using reducers. Bachman cites the difficulties of using means alternative to punishment such as understaffing or lack of education and training for staff in the use of behavioural techniques, as reasons for the adoption of reducers. He reviews some of the literature concerned with the use of punishment with self injurious, learning disabled people, and concludes, " In light of these results and considerations, there is no good reason to permit children to severely injure themselves or to spend their early years uselessly in physical restraints...."(p. 221). Bachman (1972) draws this conclusion on the strength of case studies which do indeed show optimistic results for this treatment approach. Tate and Baroff's seminal 1966 paper is cited, describing the reduction of self injury and an increase in adaptive behaviours. Bucher and Lovaas' (cited in Bachman, 1972) seven year old head banger is also cited, whose self injury decreased from 3,000 self injurious responses on the first day of treatment to zero, the child being given only twelve electric shocks. Equally successful work by Corte et al. (1971), Hitzing and Risley (1967), and Yeakel et al. (1970) is cited as support for the use of reducers in work with the self injurious learning disabled client.

Rincover (1986) also reports the efficacy of punishment, raising, however, two difficulties in

its use. The first is the whole moral/ethical problem and the second concerns the lack of generalisation in the post-therapy environment. It is evident that people will learn to distinguish between carers who do, and those who do not, administer punishment, and also environments in which it does and does not occur. Further, if clients have been removed from their normal living environments for the "therapy", one would assume that there are variables within that living environment which have maintained the behaviour, which will not have changed during the individual's absence. To attempt to implement a thorough punishment programme within the living environment would prove expensive in terms of staff ratios and training and thereby counter Bachman's argument for its use.

Singh, Dawson and Gregory (1980) recognise the ethical difficulties of using strongly aversive treatments with a client group unable to give informed consent and, therefore, examine the use of milder aversive stimuli. These include such punishments as: having ammonia held near one's face; having cold water mist squirted into one's face; having lemon juice in one's mouth; facial and visual screening. They acknowledge that, "more benign and less aversive stimuli... do not produce complete response suppression in the more difficult cases" (p. 87). The authors' work supports Rincover's criticism on the grounds of generalisation, as it describes work with two profoundly disabled people whose self injury was reduced dramatically during treatment, but which recovered during the generalisation phase. For neither of the two clients did the behaviour recover to pre-intervention levels. The behaviours gained during respite from self injury are maintained by other reinforcers.

As the studies thus far described illustrate, the adoption of this approach calls for a narrowing of focus on the part of the carer, to exclude issues which lie outside the environment/ individual

interaction. Thus one is able to side step questions of : the emotional life of the self injurious individual; the part played by the carer in that life; emotional and psychological history; changes and growth in client and carer. For the carer, the role adopted within the behavioural framework is that of programme implementor. Those providing direct care for the self injurious individual respond to the behaviours in a defined manner. Thus, again, the possibility of and need for engagement in the world of the self injurious person is removed and the relationship becomes a distanced, 'clinical' connection.

"NON - AVERSIVE" APPROACHES

As a reaction to the distancing inherent in behavioural approaches, throughout the 1980s, there was a growth in the trend toward non-aversive intervention with people who present with challenging behaviours. One of the leading voices in this movement, John McGee (1987) suggests that until the commonality of the human condition is recognised in relationships between carers and clients, there can be no amelioration of the clients' unhappiness. Interventions must reflect the philosophy of unconditional valuing, sharing, warmth and mutual growth. McGee (1987) cites cases where unconditional acceptance of the individual has led to an alleviation of their challenging behaviours. A growing body of research attests to the usefulness of a gentle teaching approach, but much of this research lacks rigour or follow up.

Mulick and Kennedy (1988), although discussing principles of normalisation rather than gentle teaching, do raise a pertinent point in their article : that the adoption of a policy first, and the search for data to support it as a consequence can be costly in human terms for the people who use services. The rhetoric associated with gentle teaching (see McGee and Menolascino's 1991 publication) assumes that the willingness to be with and for the disabled is a prerogative only of

those who adopt this approach, which reflects a worrying evangelical trend prevalent around the disability movement in the late 1980s and into the 1990s. Latterly however, gentle teaching has become part of the mainstream : an approach practitioners may choose to adopt, dependent upon philosophy, situation and client need, rather than as the holy grail. The practitioner adopting this approach needs the ability to enter into the other's emotional world and this issue of empathy in nursing is one which will be addressed in the next chapter. Any 'professional distance' between the client and carer is clearly inappropriate and again, carers need to be emotionally articulate and insightful. Academic debate has centred around whether Gentle Teaching is a new approach or whether it is merely a re-hash of non-aversive behavioural techniques, imbued with humanistic rhetoric. Other theorists have argued that the emphasis on solidarity disguises the case that gentle teaching offers nothing new. Nurses have always been in a position, and since the Nurses Midwives and Health Visitor's Act, 1979 have had a professional responsibility, to act as advocates for their clients. Whilst the extremes of behavioural intervention discussed above have attracted much attention, they have also deflected attention from the majority of practice : the aim being the improved quality of life for people with learning disabilities.

NEWER FRAMEWORKS

Whilst recognising the problems inherent in the use of pharmacological, aversive or

behavioural control of people with learning disabilities who may challenge others, as a society we do not wish to meet the level of investment in this group which would enable ameliorative or even appropriate staffing. The ideological changes through the 1980s to a social care basis have been used to lend a pseudo-respectability to this attitude. If all that is needed by people with learning disabilities is an 'ordinary life' then professional intervention is unnecessary. Simply providing homes outside a hospital setting is seen as fulfilling our communal responsibility and acknowledgement of further, or more expensive need, can be avoided by the interpretation of current philosophies and ideologies, that people with learning disabilities are 'just like us'.

The paradigm shift within the caring professions away from an emphasis on the scientific, and more toward human skills and qualities, augers change in services caring for those with learning disabilities and self injurious behaviour. However, the incongruities within the various fields of professional practice, social policy and economic reality need to be addressed. Whilst, as described above, the social policy drift is toward social, 'normalised' care for people with learning disabilities, the purchaser/provider split within care provision has placed an emphasis on 'product' rather than 'process'. To address the former, the normalisation/ Social Role Valorisation movement provided a framework which was clear and unambiguous at a time when an alternative to institutional care was needed (Emerson, 1992). This simple view of care contributed to a sound basis for the closure of large hospitals and the establishment of community based 'normalised' services. Further, the translation of these principles into a set of easy to understand guides have made Social Role Valorisation an attractive option. Whilst few would question the validity and rectitude of the assumptions and expectations of the framework, it has suffered the same fate as both the medical and behavioural models outlined earlier, of dilution and abuse within services.

Emerson (1992) suggests that normalisation as a recognisable entity emerged at the end of the 1950s in Denmark as a response to the recognition of need for ordinary experiences and opportunities for people with learning disabilities. At this time, the emphasis lay in, "making available to all mentally retarded people patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life of society" (Nirje, 1980, p. 30, in Emerson 1990). The characteristics outlined by Nirje at this time (e.g. progression through the stages of the life cycle, ordinary rhythms of days, weeks, years) are obviously at odds with the lifestyle imposed by institutional care. In his paper, Emerson reflects the changes which have occurred in Social Role Valorisation thinking over the last forty years and within this shift lies the latter issue : that of the emphasis on product rather than process in care provision.

For early workers normalisation philosophy was about rights : about ensuring that people with learning disabilities received and exercised the same rights as other citizens and that this recognition was reflected in the quality of life this group enjoyed. The shift, Emerson suggests is from a concern with rights to the development of a social theory concerning the perception of social groups which may be utilised for any 'at risk' group. Integration has become central to the use of Social Role Valorisation as reflected in O'Brien's (1981) service accomplishments, which represent an influential framework in U.K. service provision.

This pattern for care provision has been adopted wholesale by the Trust within which the research participants work : it forms the focus of the mission statement; it features largely in the philosophies of all services within the trust. The creation of socially valued roles has become the *raison d'être* of service provision - integration has become an end rather than a means.

However, as Elks (1994) points out Wolfensberger's claim that from the adoption of socially

valued roles will spring the gamut of acceptance and integration is evidently (at best) over optimistic and he cites the experiences of other groups as support. For example, black people may hold socially valued roles (in terms of employment) and yet suffer discrimination in other realms of their lives. "Culturally valued roles may be necessary to live culturally valued lives and valued personal identities, but are not sufficient" (Elks, 1994, p. 269). The other side of this conclusion is perhaps more pertinent here; that the adoption of valued social roles will not solve many of the personal and emotional difficulties people with learning disabilities may have and thus not address the individual's self injury. Whilst the person continues to self injure, avenues to more valued behaviours and roles remain closed.

An example of this is the expectation of community integration and participation in using Social Role Valorisation as the guiding principle in care provision. Certainly, the move out of institutions and into 'ordinary' housing has improved individuals' living environments and made physical integration possible, but the literature paints rather a bleak picture. From early work in the field (Edgerton, 1967) through the 1970s and 1980s (Gollay et al., 1979, Zetlin and Turner, 1984) the literature suggests to us that rather than embracing people with learning disabilities, the community tolerates (at best) or rejects them. Many of the stories individuals tell of their move to 'the community' are tales of isolation and loneliness. Thus direct carers work in often rather isolated conditions, attempting to promote integration into an unwelcoming community and are often totally unprepared and ill equipped for this task. With the emphasis on product rather than on process, purchasers of care may be interested in numbers of contacts with the local community (e.g. visits to pubs, shops) made by the learning disabled person, rather than the purpose, meaning or quality of such contacts. Thus, living in an disabled person. Living in an area which used to contain two large hospitals for people with learning disabilities, I frequently see people in local supermarkets who may be distressed,

ordinary life opportunities and chances for people with learning disabilities, but we do appear to be at risk of collectively denying any need for special care or intervention. Thus, in the same way in which the adoption of a purely medical or purely behavioural approach is inappropriate, one cannot expect the adoption of a different set of principles to address the complex issues involved in self injurious behaviour.

This literature review aims to give some insight into the complex historical and professional situation in which those who care for people with a learning disability and self injurious behaviour find themselves. The approaches which have been, and are being, taken toward the behaviour shape and influence current practice : the people practitioners care for are also shaped by previous care models. The staff involved in the research work within the practice and academic atmosphere outlined above and the people for whom they care are the survivors of these ideological changes. These models have shaped and continue to shape the work undertaken by carers, their definitions of their work and relationships with learning disabled people and the parameters and limits to that work. This research attempts to recognise and acknowledge the echoes of this history in the research as part of the process of growth and change in service provision. How care is framed also sets boundaries for the kinds of questions which can be asked about it, the way in which these questions can be asked and the answers to them. These issues of the boundaries set by knowledge form the focus of the next chapter which addresses the issues of knowing in nursing. It traces the epistemological history of the nursing profession and attempts to highlight some of the problems which those who care for people with learning disabilities have in differentiating their own professional history from that of general nursing. Professional history is one of the factors which forge the boundaries of

knowledge and thus directly affect the parameters of this research.

APPENDIX ONE

SELF INJURY AND I.Q. IN SUBNORMALS (SIC)

I.Q.	TOTAL	SELF INJURY	% SELF INJURY
O - 19	143	42	29.4
20 - 35	146	26	17.8
36 - 51	144	15	10.4
52 - 67	142	8	5.6
68 and over	51	2	3.9

From : Ballinger : 1971 : Minor Self-Injury

In : Murphy and Wilson (Eds.) : 1985 : Self-Injurious Behaviour

B.I.M.H. Publications

CHAPTER THREE

KNOWING IN NURSING

EVOLUTION

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KNOWING IN NURSING

EVOLUTION

In order to clarify the epistemological context of the research, this chapter will seek to explore the pertinent issues around the emergence of contemporary ways of knowing in nursing and link these with the research methods used. Questions addressed in the last chapter around the frameworks and models used in the care of people with learning disabilities are important here as they provide the 'direct care' aspect of the broader changes which are discussed in this chapter. How one perceives care is dictated by the prevalent political, economic and professional environment and this chapter offers a discussion of the literature around care in nursing. The influence of these two threads – the evolution of knowing in nursing and the nature of care – will be considered within the context of the move away from the dominant scientific/medical discourse and nursing's search for a replacement. Within this chapter, the issue of the dominance of 'general' nursing will also be addressed as fundamental to the way in which disability care has been overshadowed by this discipline.

The historical, social and ideological threads which run through the last chapter and this one, serve to place the research participants and me in a context which will illuminate the current work. The research participants practice in a service which has strong roots in 'asylum' care. The changes in care/treatment approaches discussed in the previous chapter reverberate

through their work : the people they care for are survivors of these changes; their work places and patterns reflect this history; their language is resonant with these models. The research process also reflects these threads and the following chapter outlines the method chosen on the basis of the epistemological changes discussed below.

It will be argued that the current knowledge and practice base within nursing can be understood as a product of the evolution of a (more broadly) largely female profession/occupational group within the health care arena where power has rested in the hands of the largely male medical profession (Savage, 1987). This historical approach acknowledges the differences in both the professional and social histories of 'general' nursing (caring for the physically ill) and 'asylum' nursing (caring for people with mental health problems or learning disabilities). The factors which divide these issues most sharply are those of class and gender. 'General' nursing has been framed as an occupation which emerged as a female, middle class profession. 'Asylum' nursing has been a largely male occupation and remains more gender balanced. Other long-term care client groups (for example, the elderly) whilst by virtue of the continuing nature of the care needed and by their placement within institutions may well have been at risk of 'asylum' care were (and are) cared for by 'general' nurses who bring with them the historical and professional socialisation which will be discussed below. Whilst recognising that the care situation is altered by these dynamics only within the last few years have the histories of disability and disability care been investigated. The dominance of care for the physically sick within the profession is evident in many ways : the balance of material in 'generic' journals; the curricula for nursing courses; the re-naming of 'general' nursing as

'adult' nursing; the professional backgrounds of most nurses within education and research. Thus, the dominant epistemology is that of 'adult' nursing and as such, the relationship between medicine and nursing is one of the major themes within the evolution of nursing research in its attempts to establish alternatives to positivistic ways of knowing.

As a profession, nursing straddles the divide between the social and physical sciences uneasily (Porter, 1993). The emergence, or process of emergence from medical domination for all forms of nursing has heralded an opportunity for nursing to examine its philosophical, particularly its epistemological roots (Carper, 1978). No one clear way forward for nursing has presented itself as the former certainties of the medical model are relinquished and the last fifteen years have been years of flux and of uncertainty for many individuals and for the profession. This position has been made more uncertain since, as Clay argues (1987), nursing's history as separate specialisms with different interests leaves it now in a weak position. The current movement of nurse education into further and higher education may be another stage in this evolutionary process, as the professional socialisation achieved so firmly through a tight-knit apprenticeship system dissolves yet further.

HISTORICAL PERSPECTIVES

The nurse's role has traditionally been viewed as supportive to the doctor. The image of the nurse as auxiliary carries across all fields of nursing - the surgeon or physician being seen as the prime mover in health care (Maggs 1983). Indeed, the way in which nursing saw itself in relation to medicine is strongly reflected in past patterns of education and practice and in legal

responsibility. That medical science as the dominant ideology had an enormous impact on nursing knowledge and research may be one of the reasons for nursing's current difficulty in finding other ways of knowing.

The history of nursing is popularly presented in terms of its famous individuals - a Whig perception of a smooth transition from Sarah Gamp images through to 'angels of mercy' images. However, this simplistic account ignores many of the historical and current divisions within the profession, as addressed by Clay (1987) and the complex relationships between society and nursing and society and women (Baly, 1980). Obviously over nursing's early evolution there were manifold social and political changes which influenced the direction and growth of the profession and some of which are reflected in the uneasy relationship between 'general' nursing and 'asylum' nursing. This relationship (coupled with other social and professional forces) has resulted in questions around the : need for; fitness of; appropriateness of nurses for people with learning disabilities which have rumbled through the decades, emanating both from within and without the 'disability' world. Despite these questions, learning disability nursing has remained firmly within the family of nursing and the adoption of Project 2000 patterns of education proved an important marker in the continuation of this relationship. Thus the histories (and perhaps destinies) of the specialisms remain firmly linked. This next section of the work will explore the more generic historical issues, highlighting similarities and differences as appropriate.

Whilst post-Florence Nightingale nursing has been largely viewed as a middle class vocation, Dingwall, Rafferty and Webster (1988) point out that prior to her reforms, nursing was

already beginning to change. The mid - nineteenth century witnessed care being given by women who were little more than domestic servants in hospitals, and by 'handywomen' in the community. As Vincent-Pryer (1990) illustrates, a lack of training does not equate with a lack of competence but the Poor Law Amendment Act of 1834 had a devastating effect on the care of the sick. Most of the care in workhouses was given by peers as they did not have to be paid market wages (Maggs, 1983). Care outside institutions continued to be offered to poor people by poor women for whom nursing may have been just one of the roles they undertook in order to earn a living (Dingwall et al., 1988).

Change in nursing appears to have been initiated by change in medicine, which demanded more able and skilled 'carers' to support medical practitioners. Nurses began to be distinguished from servants in hospitals and the practice of training nurses within the hospital setting spread (Maggs, 19 83). The 1904 Select Committee on the Registration of Nurses suggested that this change occurred from the 1880s onward, with the expansion in the hospital system, and the subsequent demand for more and better trained nurses. Thus, the influence of nurse reformers at the time may not have been the revolutionary process so popularly accepted. Florence Nightingale's life and work has attracted many myths, and that of her transforming nursing into a middle class vocation is one of them. Moral training and self discipline formed an important part of the role of the New Nurse, traits which might be considered as gained from a middle class value set. However evidence from Maggs, (1983) and Dingwall et al. (1988) shows that nursing continued to recruit largely from the working classes with a proportion entering it from manufacturing work along with many of

the 'excess' women from the middle classes.

Thus the representation of nursing as a vocation for middle class women (e.g. Stewart, Bedford Fenwick, cited in Abel-Smith, 1960) struggling for professional recognition supposes that the leaders of the group represent the interest of the mass of its workers (Rafferty, cited in Pearson and Vaughan, 1986) which may not necessarily be the case. One important difference here is that which is currently referred to as 'skill mix'. Whilst care in acute settings has been offered by qualified nurses and those in training, asylum care has a history of the employment of unqualified carers - a point to which I shall return. This means that those engaged in direct care were likely to be quite different in terms of motivation and aspiration. This is one of the divisions to which Clay (1987) refers and is also one of the influential forces shaping this research : the differences in history and image between the general nurse and the asylum worker. Whilst arguably not as common in 'general' nursing as popularly believed, the middle class, educated woman is almost entirely absent from the history of asylum care and the impact of this on the occupation's history and on its current work and status is considered below.

Carpenter (from Davies, 1981) suggests that nursing history should be seen as, 'one chapter in the history of labour' and in fact, the strength of labour movements within the workforce has shaped working patterns and concerns within asylum work. Unionisation which has been, and continues to be, a focus of concern for 'general' nurses has strong roots in asylum workers, whether professional/trained nurses or unqualified care staff. Care patterns within

asylums for the mentally disordered were an offshoot of the Poor Law / Workhouse system :
"..workhouses, prisons and asylums were physically similar and served overlapping functions.." (Dingwall et al. 1988). It would appear that, at this time, the learning disabled were treated in the same way as other perceived deviant groups. Care for this group emerged only as a separate entity at the turn of the century and was confirmed by the 1913 Mental Deficiency Act. However, owing to poor conditions of work and pay, and the general pessimism surrounding care/cure issues for this group, it was difficult to attract nurses, despite the establishment of training and examination in Mental nursing earlier than in the care of the physically sick (Dingwall et al., 1988). The difficulty of recruitment to professional nursing in the care of those with a mental health problem or a learning disability is cited by Dingwall et al. (1988) and Maggs (1987) as the reason for the employment of large numbers of untrained workers within the asylum system.

With the reframing of mental disorders as medical rather than moral problems in the last years of the nineteenth century, the pattern of education and employment of general nursing began to spread to the asylum. The Medico-Psychological Association (an organisation dominated by doctors) introduced an educational programme and examination for asylum nurses in 1891 - which was phased out as late as the 1950s in favour of the General Nursing Council's registration. None of this would have occurred without the sponsorship of the Asylum Worker's Union, but difficulty in attracting workers remained. These difficulties have continued into the recent past ; witness recruitment drives in areas of high unemployment in

the 1940s, in Ireland particularly and in Commonwealth countries in the 1960s.

Thus nurses caring for people with learning disabilities worked within a medical model, which views disease or disorder within the individual as a manifestation of malfunction of body parts. This Cartesian approach to the individual leads to particular ways of approaching disease (as illustrated in the previous chapter on pharmacological treatments of self injurious behaviour) and more broadly, of seeing people and their relationships with their world. Parse, Coyne and Smith (1985) describe this approach as the 'man-environment-totality' paradigm within which people are seen as reactive to their environments and their behaviour is accessible to both measurement and prediction. Working within this medical model does not auger well for those caring for people who will not 'get better'. If culturally our aim is to restore people to their normal state, i.e. functioning effectively within society, then the care given to these groups is 'wasted'. Hence, it is perceived appropriate for these groups to be cared for by the untrained or those with minimal education and training. Care being delivered by untrained assistants is a pattern which runs through the history of asylum care and continues to exist. Whilst 'community care', measured against poor institutional care, appears to be a move forward for the learning disabled, economic forces ensure that the patterns of care outlined above continue, with even the most needy people with learning disabilities being cared for largely by unqualified workers. The received practice of normalisation/Social Role Valorisation theory is manipulated to support these economic realities - all that is required for the learning disabled person is the opportunity to gain normative experiences, and this does not require professional intervention.

Reflection upon the position into which this history casts women is somewhat gloomy. Within the realm of caring for the sick - popularly seen as an opportunity for women to break away from home and family constraints - we see women being forced into very similar roles as those within the home, which Littlewood (from Holden and Littlewood, 1991) described thus : "Nursing (as) an extension and codification of woman's nurturant role as mother" (p. 148). Men within the asylum system fulfilled quite a different role , often coming to the work as other forms of employment faded (Maggs, 1983). It is interesting to compare and contrast this with the current changes in nursing more broadly, which is positively recruiting men as a response to demographic, economic and social changes. Asylum nursing was hardly open to women who wished to make nursing a career and those who did move across from general nursing were resented, and continued to work under a medical regime , whose head, the medical superintendent, wielded 'spectacular power' (Dingwall et al., 1988). Recent work by Davies (1995) adds a further dimension to these gender issues. In her discussion on the historical, sociological and political roots which have shaped our view of caring and of carework, she suggests that the bureaucratic rules and frameworks which nursing relied upon so heavily were a reflection of how the public care world adopted the masculine ethos. Issues so prevalent in nursing practice - impartiality, role structure and function, detachment - were a reflection of importing male relationships and values into a female occupation. Nursing's recent claims to autonomous practice may also be seen in this light. However, the rigidity and formality of asylum care may, with this work in mind, be seen as having a two fold basis : firstly, that of the adoption by the 'caring' professions of this masculine agenda, and secondly, the high proportion of men in asylum care.

NURSE EDUCATION

The constraints of the medical model lead to quite specific ways of working and of preparing students to work as nurses. Education for all nurses reflected the domination of medicine. Nurses were lectured to by doctors, learned about disease patterns, signs and symptoms and memorised the routines, practices and procedures deemed appropriate for the patient. That the nurse's attention should focus on the illness first and the person second is still visible in the division of nursing curricula into 'surgical', 'medical' etc. nursing studies. People were viewed as biological systems whose balance (either physical or mental) had been disturbed by a pathogenic organism or pathological malfunction. Doctors worked in an individualistic and heroic fashion to cure: nurses fulfilled a supporting role in providing an environment conducive to healing and in following through the prescriptions of the doctor.

In a culture in which curative and caring functions were equally valued these different roles would present no difficulties for either occupational group. However, within Western culture, the curative role adopted by the medical practitioner (surgeon / physician) has been, and still is more highly valued than the caring role. As evidence for this we may note the differences in salaries paid to doctors and nurses, particularly those at the apex of their careers; the education/training standards required; the relative media images; the frequency of appearance of each professional group in the serious media etc. (see Gray and Pratt, 1991). This image of the pioneering doctor striving to save life is also reflected in the health care system in Britain. The individualism which permeates Western culture generally is reflected in the way in which the medical profession organises itself: the doctor/surgeon battling against

illness, aided by supportive and previously interchangeable nurses.

Nurse education until relatively recently, served to reinforce these images of obedience and efficiency (Maggs, 1983). This is reflected in repeated rejection by the profession of reform to nurse education. Abel Smith (1960) and Clay (1987) reflect upon the dilution of government suggestions for change, opposition springing largely from the influential Matron group, through the power of the Royal College of Nursing and the General Nursing Council. The Wood report (1947) was one of the first to suggest the unshackling of education from service providing a curriculum composed of common core and specialist modules. The fate of the Platt report (1964) and the Briggs report (1972) are depressingly similar, with established power bases blocking and internal wrangling hindering educational reform (Clay, 1987).

Education for nurses for the learning disabled had fitted the pattern of reflecting the dominant power group. For many years the curriculum was dominated, inappropriately by knowledge and skills derived from caring for the physically sick particularly in the curricula from the General Nursing Council which was dominated by 'general' nurses. Indeed, it is only within the last fifteen years that a single qualification (i.e. a registration in learning disability care) has been recognised as adequate: prior to this, nurses for the learning disabled were advised to 'do your general'. However, through the 1970s and 1980s more psychological and social aspects of care entered the curriculum, often outreaching practice in terms of vision. The 1982 curriculum particularly reflected a values base of egalitarianism, of respect for individuals' human, legal and civil rights and of facilitating as normal a lifestyle as possible (E.N.B. 1980). However, in the 1980s a large proportion of residential care for people with learning

disabilities remained within institutions and it was - and to some extent still is - within these environments that student nurses gain their socialisation. The 'spectacular power' to which Dingwall et al. (1988) referred had by this time begun to wane but the medical staff still comprised the most powerful professional group within this setting.

The establishment of Project 2000 patterns of education, taking nurses to at least Diploma level, has begun to place nurses in a position from which they may challenge the dominant ideology. The ever-increasing base of theory in nursing, coupled with expanding research in and about nursing is offering the opportunity for nursing practice, which is interdependent with the practice of other professional groups in the health care arena. The problems of a history so enmeshed with that of a discipline which has a different base and which employs (relatively) few qualified carers continue to dog nurse education. Many curricula reflect the dominance of 'adult' nursing within the common foundation programme, placing a heavy emphasis on anatomy and physiology, pharmacology etc. and little on communication and relationship skills, social policy or psychology. In the care of people with a learning disability where the appropriateness of the medical model has always been questionable, specialist education does equip nurses with a knowledge base through which they can care for people in a facility-independent fashion. (Kay, Rose and Turnbull, 1995). Degree and post-graduate courses are now easily accessible to nurses which will help to redress issues of educational imbalance between professional groups. However, this very rosy picture of education for carers for the learning disabled must be set in the political context of the purchasing and

provision of care. Cost restrictions are to the fore and these may act to maintain patterns of care delivery from the past.

PRACTICE

As chapter two suggested, the revolution which has taken place in nursing practice over the last twenty years (in the U.K.) has highlighted the importance of nurse-client relationships. Yura and Walsh (1988) claim to have, "discovered and promoted" the nursing process from 1967 onward in the U.S.A. whilst acknowledging reference to it in the nursing literature before this date. Griffith Kenney and Christensen (1986) view the movement from task allocation to a systematic assessment, delivery and evaluation of individualised care as being a more gradual process - citing Knowles, Orlando, Kelly and Johnson, all from the 1960s as important figures in the change process. Certainly, through the 1960s nursing was moving toward the establishment of its own knowledge and research base and a realisation that nursing's focus was different from that enshrined in the medical model. Central to this change was the overt need to deliver individualised care and a framework through which this could be achieved. Definitions of this framework - the nursing process - vary and Kershaw and Salvage (1986) present differing definitions from Marriner, McFarlane and Castledine, Roper, Logan and Tierney. Each of these contains some elements as central: individualised care delivery; systematic approach to care provision; autonomous decision making; the nurse/client relationship.

The emphasis on individualised care has led to different patterns for the delivery of care - primary nursing, team nursing, key worker systems. With a smaller number of nurses involved with each patient/client (Griffith-Kenney and Christenden, 1986) the relationship between the nurse and the patient/client has become more important. Much nursing theory and research reflects this emphasis on the professional care relationship and, indeed, the nature of care itself.

A major difference is apparent here between nurses involved in 'adult' care and those who care for people with learning disabilities. Increasingly, a combination of social policy, changes in medical practice and economic constraints are making contacts between 'adult' nurses, in hospital or in the community, and their patients shorter : people stay in hospital for the minimum time possible; much care at home is given by families. In contrast the relationship between paid carers for people with learning disabilities is, by its nature, longer term. Residential care workers may be involved with individuals on an almost daily basis for many years. Community nurses will similarly have contact with individuals and families over many years. Much of the literature which is reviewed later in this chapter which explores the nature of care is based on the acute setting and may miss many of the more important elements of longer term care. However, before addressing these central issues, it is important to consider the patterns of knowing and reflection which nursing is beginning to establish for itself which make it possible to ask questions concerning the nature of nursing itself.

MOVING AWAY FROM MEDICINE

The bio-medical approach which influenced all aspects of nursing for so long is underpinned by a belief set regarding people, science and health, with which nursing is beginning to take issue. Within this totality paradigm (Parse et al. 1985) reality is seen as independent of human experience. The adoption of science, with the emphasis upon objectivity, offers a way of revealing what is seen as the truth, rather than a truth. This prevailing professional view dictates the way in which doctors approach their work : the patient is seen as having disturbed homeostasis and the doctor's task is to correct the imbalance. We may use the mechanic analogy here that of the doctor tinkering with the patients parts, either directly through surgery or indirectly through medicine, to correct the malfunction. If consideration is given to the role played by other factors in the presentation of 'abnormality', then the simple cause and effect model begins to falter (Nagle and Mitchell, 1991). Whilst these ideas may present a stereotype of the way in which individual practitioners view their work, the way in which health services are provided in Western cultures make it difficult for individuals to break away from this approach to any significant degree.

The adoption of any model will have implications for the 'reality' one perceives. The medical approach strives for objectivity - the doctor as rational, treating patients and researching through his reliance on his belief in universal laws (Polit and Hungler, 1987). The move reflected in the last chapter from a medical to a behavioural approach in a search for a 'cure' for self injury incurred the same difficulties as behavioural science sees itself as just that - science. This striving for objectivity misses the very point that the utilisation of any theoretical

approach will dictate which questions can and cannot be asked and what form the answers will take. The assumption is that , "data can be collected without recourse to the theoretical assumptions of the collector" (Porter, 1993, p. 137). Munhall and Oiler (1986) comment that the scientific approach can offer a rewarding view of some situations but that science rather negates its own offering by denying that it represents but one facet of the a situation. However, the belief that science represents the truth is strongly embedded in Western European culture. Many texts on nursing research do not question this belief that scientific investigation reveals an objective truth (Polit and Hungler, 1987) - thus the journey toward the acceptance of multiple realities is a long and arduous one in nursing. These issues of the acceptance of multiple realities will form a focus for discussion in the next chapter.

A second pertinent tenet of the bio-medical approach from which nursing is distancing itself is the importance of quantification in working with people and in research. The emphasis within the natural sciences on the observable and the measurable presents major difficulties within the wider realm of care. For many of the issues with which nursing concerns itself and, indeed, with which this piece of research is concerned quantification is an irrelevance. Emotional / psychological / spiritual aspects of people's lives and experiences present enormous difficulties to the prospective quantitative researcher (Porter, 1993).

Nursing research has tried to echo the methods used within the natural sciences and medicine in research as these seemed to offer the means to achieving academic and professional recognition. However, this framework has excluded questioning on issues of

the intention of care, the nature of care etc. The move away from scientific positivistic methods in research has accompanied the changes in both education and practice. As a profession, nursing's growing self confidence has led to an increasing willingness to move away from medicine and the higher levels of education offered to nurses facilitate the understanding and adoption of other methods of research and practice. Further, the move toward individual care delivery and the impact of this on the nature of nursing work, has raised questions other than those which science can answer. Munhall and Oiler (1986) suggest that language and language use are markers of a paradigm and the language shift within nursing has been from, "the medical, atomistic, causal model to a distinct, nursing, holistic, interactive model" (p. 12). This piece of research represents an example of this move away from a positivistic stance. It addresses questions of motivation and emotion which would be difficult to approach quantitatively. Further, as the next chapter will argue, an attempt to use a quantitative approach might be inappropriate as these issues require fluidity and movement in the research methods used in order to reflect fully the research participants' views.

I would suggest that the differing foci for medicine and nursing make this separation of paradigms inevitable. Exactly what the foci for nursing are is a question which has bedevilled the student of nursing for many years. As a neophyte profession theory, or to be more precise theories of nursing are beginning to emerge. Cultural differences within nursing theorists are apparent in their work, partly as a reflection of differing health care systems and differing educational and licensing/registration requirements internationally.

KNOWLEDGE IN NURSING

Four themes emerge as central to theories of nursing, and in nursing models through which nursing theory is actualised. The nature of the person; the nature of the relationship between people and their environment; what is health?; what is nursing? are issues which theorists address in the attempt to clarify the bases upon which the profession's practice and theory is set (Fawcett, 1984). Some consideration of the issues addressed in the previous chapter around the question of the aetiology of self injurious behaviour in people with learning disabilities and the way in which we care for them will illustrate the importance of these themes, which, as the review demonstrated, are often viewed separately. However, nursing theorists are suggesting that these themes need to be pulled together to give an holistic view of the individual and the care s/he needs and receives. It is the view taken of these which differentiates theorists : for example, Dorothy Johnson (cited in Rhiol and Roy, 1980) sees the patient as a behavioural system made up of subsystems and the focus of nursing intervention is to restore the equilibrium of behavioural functioning. Maintaining the wholeness of the individual is, by contrast, the dominant theme in Levine's (1973) work and nursing intervention aims at facilitating the patient's adaptation processes.

The stance taken toward the themes by theorists and practitioners can vary enormously but Benoliel (1984) among others argues that nursing is growing into a new paradigm which asserts multiple realities. And this indeed is the stance I take in relation to the research. Within any given situation the participants forge their reality through interaction and perception. The 'reality' presented in this piece comprises my interpretation and

understanding of that reality. As such no claim is made on the truth, rather on a way of knowing. Obviously, this move away from the perceived 'proven' certainties of a positivistic account raise immediate issues around validity and congruence in the research, which will be addressed in the next chapter.

How is knowing in nursing to be constructed? For this piece of work, I have chosen to use Carper's (1978) framework which suggests four patterns of knowing. The first of these is empirics - the generation of theory from factual evidence. This asks that we organise knowledge about the world, to form theories which subsequently inform practice. The form which this piece of research takes (the generation of theory from data) demonstrates this tenet. The second pattern outlined by Carper (1978) is aesthetics, with the emphasis on relationships and empathy. Given the question which is being asked in the research, the importance of this way of knowing to the work is evident. The third way of knowing which Carper suggests is that of personal knowledge, which can form an area of difficulty for the positivist. The epistemological stance taken in this work values and utilises personal knowledge, as discussed in the following chapter, recognising the construction of reality by all participants within the care situation. The final pattern suggested by Carper (1978) is ethics in which the nurse's knowledge of pertinent legal and moral frameworks, ethical theories, professional requirements and personal value systems guides their practice. This final way of knowing is reflected throughout the piece in an attempt to respect and protect the veracity of each individual's way of being with and caring for people with learning disabilities and in the attempt to improve practice.

The discussion in this chapter around social policy and nursing and in the previous chapter around intervention will have indicated that the type of explanation attempted in this research is unfashionable as it calls for prolonged and to some extent intangible work. Socially based, conscious explanations would suit the political mood much more closely. However, I feel that the care situation within which the research participants work presents a clear illustration of the complexity of the nature of carework and of the care environment, that they demand attention and exploration. The emotions expressed by the research participants about their work reflect such complex and sophisticated patterns of growth and change that they demand an intensive and subtle approach to provide from them an explanatory theory for caring about this particular client group.

THE FOCUS OF NURSING

The question of what realms of human enterprise may be considered the business of nursing changes and evolves. Our concept of health, the health care arena, changes within the profession, will all contribute to the shifting of ground within nursing concerns. As care becomes less institution oriented with the implementation of the N.H.S. and Community Care Act (1990) so practitioners will be required to develop facility- independent skills and to meet those needs considered to be 'nursing' concerns within ever more diverse settings. This need to identify specifically the role/purpose of the profession has been particularly acute in learning disability nursing. The validity of the role of the nurse for the Mentally Subnormal /

(most recently from the Department of Health (1995) and the Royal College of Nursing (1995) have explored a variety of options for the future of this group.

Many attempts have been made to define the realm of nursing generally and indeed, what it is that nurses do. The American Nurses' Association suggest the following among phenomena which are the business of nursing : pain and discomfort; emotional problems; distortion of symbolic function; problematic affiliate relationships. Patterson (from Munhall and Oiler, 1986) attempts to address this question. She suggests a list of five issues : comfort; nurturance; clinical; empathy; all-at-once, this last representing a holistic awareness of the client's needs. These examples illustrate how nursing is beginning to focus much more on the meanings and values that actors ascribe to their own situations (Taylor, 1993) whether the actor is a client, relative, nurse or other carer. Indeed, the whole concept of care has recently come under scrutiny within the profession, Barker et al. (1995) even arguing that it has no place in nursing.

CARING IN NURSING

The literature here is vast, growing, and unclear. Theorists differ over: the nature of care; whether caring is an attribute, a trait or a set of behaviours; if it is a set of behaviours, then which of them comprise care?; the place of caring in nursing ; and, as above, whether care and caring has a place in nursing. One thread in the debate which this piece of research suggests has not been addressed in the literature is whether caring in short and long term care is inherently different. The huge range of opinion voiced over the whole issue of care and caring

reflects, I feel, the main thrust of the research : that caring in itself necessitates ambivalence and tolerance of that state ; ambivalence toward the role and the behaviours it occasions; ambivalence toward the person cared for; and ambivalence about one's own feelings about caring. Enclosed within this debate is another which concerns the issue of empathy, which will also be considered here.

Barker et al.'s (1995) article reflects an extreme articulation of one of the issues which I perceive to be the most difficult in establishing the nature and meaning of care : which is that in the rejection of a positivistic, 'science based' view of nursing as a shadow of medicine, many (particularly N. American) nursing theorists are imbuing the debate with, "quasi religious, quasi philosophical overtones" (p. 386). The particular difficulties which Barker et al. highlight in the theoretical literature will be addressed as this chapter progresses. However, this major issue of the establishment of an alternative paradigm through which nursing may be defined and evaluated persists. This may prove to be a pivotal point on which the differentiation of 'acute' and 'other' nursing turns. As contact with patients /clients for 'adult' nurses becomes shorter and more illness based then issues of care may slip down the agenda, whilst in situations of longer term involvement the recent epistemological shifts may enable real progress in the field of emotional aspects of caring.

Current social policy, politico-economic and philosophical trends demand visible and measurable outcomes against which to judge cost. Consequently, in acute nursing, a plethora of quality assurance tools are available to meet this need. Within the realm of care for people with learning disabilities, locally designed or commercially available 'standards' proliferate.

These focus on 'product' not process (a point to which we will return) - they may, for instance, count the number of community contacts rather than understand the purpose or meaning of these - and it is within this emphasis on outcome that the nature and meaning of care itself may be lost. Whilst not wishing to suggest that outcomes of care are not important, if used as the sole measure the importance of the processes of nursing - of care - may be lost. Barker et al. (1995) suggest, in response to much of the N. American literature that care is not definitive of nursing, but that nursing re-invents itself to accommodate social shifts. The research undertaken here would suggest that caring relationships between nurses and clients continue unaffected by social policy changes because of the intimacy inherent in the 'care' situation and the humanity of both participants.

DEFINITIONS AND DESCRIPTIONS

This brief review of the ideas around caring in nursing will begin by presenting an overview of the widely varied definitions of care offered within the literature. Many writers (Radsma, 1994, McKenna, 1993) acknowledge that the concept is poorly understood within nursing and that the "religious fervour" (Radsma, 1994, p. 445) with which the debate is marked may be an effect of this lack of clarity. This can be illustrated by briefly exploring the work of two notable writers in the field - Leininger and Watson - the latter being the target of no little vitriol in the Barker et al. (1995) article cited above. Leininger proffers the following definition:

"Caring, in the generic sense refers to those assistive, supportive
or facilitative acts towards or for another individual or group

with evident or anticipated needs to ameliorate or improve
a human condition or lifeway" (Leininger, 1988).

Leininger's view of what caring is focuses on behaviour and, in the case of professional caring, on skills. She suggests that caring entails biological, psychological, social, environmental and cultural components, but the emotional component of the nurse/client relationship does not feature as part of her thought. She sees caring as the essence of nursing, caring being a set of health - directed behaviours. One difference which becomes immediately apparent here is that of the professional background of the theorists. As previously, many writers in the field that I have been referring to are 'general' nurses and as such have an emphasis on health. Despite the fact that many of them do provide a broad definition of health which could encompass the work which those caring for people with learning disabilities undertake, it is often difficult to maintain one's focus in this literature.

Watson, on the other hand, adopts a much more esoteric view of care :

"Caring begins when the nurse enters the phenomenal field
of the patient and responds to the patient's condition
of being in such a manner that the patient releases
subjective feelings or thoughts that the patient had
longed to release" (Watson, 1988).

Nursing involves personal, scientific, aesthetic and ethical human transactions. She thinks, as do other writers explored below, that care as the essence of nursing is under attack from many

quarters and that the profession should strive to maintain its caring ideal.

Other writers have referred to caring as : an ethic (Fry cited in Radsma, 1994); a science (Dunlop, 1986); a composite of activities and feelings (Griffin, cited in McKenna, 1993); a capacity (Roach, 1984); a knowledge and skill amalgam (Gaut, cited in Forrest, 1989); a therapeutic use of self (Benner and Wrubel, 1988); authenticity (Aldridge, 1994); a set of actions (Clarke and Wheeler, cited in Phillips, 1993). With such a confusing and often contradictory plethora of opinion and research attacks on the very concept (like Barker et al. above) are inevitable. Clarke and Wheeler (1992) respond to this by suggesting that there are two dimensions to caring in nursing : a definitional approach, with which we are currently struggling; and a hermeneutic approach, which describes this research - "The use of the lived and spoken meanings of the carers themselves liberates the meanings and experience of this phenomenon called care" (Clarke and Wheeler, 1992, p. 1284).

One of the reasons for such disparity in defining and describing the nature of care and, particularly, care in nursing may be the very broad nature of the 'work' undertaken. As an occupation, nursing covers activities as diverse as health education, counselling, caring for people with acute and chronic physical and mental health problems and residential work. The knowledge and skills base within the profession is correspondingly broad, as is the nature of the relationship formed with the client. Thus, encapsulating the essence of what each of these practitioners does - caring - poses an extraordinarily complex task. Watson (1988), cited above, has approached this by devising a list of ten carative (sic) factors - a definitional

approach - which would encapsulate the focus for nursing for all nurse-client interactions. Watson's work has been widely criticised as being : pretentious (Barker et al., 1995); too far away from nurses' everyday work (Dunlop, 1986); falling into the theory/ practice gap, (Morse et al., 1990). The same criticism may be levelled at Morse et al.'s attempt, which proposes five perspectives on caring : as a human trait; a moral imperative; as an affect; as the nurse-client relationship; as therapeutic intervention. Some flexibility within the description is granted, as Morse et al. suggest that, "nurses have the ability to adjust their approach and their style of interaction as they move from patient to patient..."(p. 10).

Hall (1990) suggests, rather than a taxonomy, a four component model of care, which asks for articulation of : a set of beliefs/philosophies which guide care; a set of goals/ objectives; a set of practices and acts; the emotions and feelings which accompany care. The accommodation within this model for individual carers' practice brings it closer to Clarke and Wheeler's (1992) hermeneutic approach, whilst establishing boundaries for the definition and description of care. This approach of indicating areas of interest in the discussion of care, rather than attempting to provide all-inclusive descriptions is adopted also by Forrest (1989) who, from a qualitative piece of research with 17 R.N.s, felt that the areas of focus in defining caring are involvement and interaction. It would be interesting to investigate whether these categories were specific to the particular work situation of her research participants. One of the suggestions in this piece of research is that the history of areas of concern of 'general' nursing - that which dominates theory - fails to account for the work undertaken by nurses in long term care situations, particularly in working with clients who challenge in some way. I would

suggest that the defence mechanisms which are used in 'acute' intervention situations are different in nature and in shape from those used within long term care relationships. Some differences are immediately apparent and may account for this : the gender issue which was raised earlier; the larger number of unqualified carers within this environment; the nature of the clients' difficulties. On closer examination in the research, I would also suggest that the intra psychic aspects of dealing with consistently self damaging and dependant individuals call for more sophisticated and dynamic emotional management than is apparent in the literature. These difficulties notwithstanding, the identification of areas which are the 'business' of caring might prove a fruitful move in the attempt to articulate what it is that nurses do.

THREATS TO CARE IN NURSING

Before moving on to explore the literature which is concerned more with the focus of this research, the emotional component of care, it might be apposite to explore some of the perceived threats to the centrality of care in nursing. The first of these will not be addressed in detail here as it formed the focus of an earlier section of this chapter - the perceived juxtaposition of curing and caring : "... the reality of a dominant view that values curative technologies and practices over the caring practices of nurses remains unaltered" (Radsma, 1994, p. 445). Within the context of care for those who are physically ill, the association which binds nursing and medicine, despite the fact that nurses increasingly work outside hospitals, and relatively independently of medical jurisdiction, hinders the evolution of a nursing paradigm in its own right. As highlighted in previous chapters, nursing's adoption of some of

the attitudes and language of medicine has further handicapped this move away from the dominant discourse, and, as Benner and Wrubel (1988) suggest, the association of devalued work (caring) with invisible workers (women) makes the evaluation of what nurses actually do very difficult. Nurses who care for people with learning disabilities, the Cinderella of the family of nursing suffer in two ways from this. First, because the dominant discourse has been so inappropriate for this area of care, learning disability nurses have been viewed as deviant within the profession. And secondly, because of this position, it has been difficult for learning disability nursing to either make a mark on theory and research and thus influence the ideology and epistemology of nursing. Maintaining a concept which is difficult to define - care - as the core and heart of nursing serves to complicate this issue.

One point which may be seen as an extension of the above which is raised by Hawthorne and Yurkovich (1995) is the relationship between nursing and the increasing use of technologies in curing and caring. As a culture increasingly dependent upon technological aids in daily personal and professional life, it is argued that the meaning of care has been lost. Scientific and technical interventions are being used as ends rather than as means and consequently the nurse, the client, and their relationship are overlooked. Some practitioners are involved in situations where there is a heavy reliance on both science and technology, for instance, those who work in intensive therapy units. These 'supports' to the practitioners' work with individual patients and clients do not in themselves form a threat to the 'care' element of their job; rather, the threat lies in the cultural perception of one's technical understanding and abilities being of more value than one's emotional knowledge and skill.

The cultural attitudes reflected above, coupled with political and economic changes over the last fifteen to twenty years have led to a situation in which nursing is being evaluated in terms which are, to some practitioners and theorists, alien. To return to an issue raised briefly earlier, Astrom et al., as far back as 1990, were suggesting that purely quantitative measures for gauging the effectiveness of nursing are inappropriate : one should measure nursing in terms of process rather than, or as well as, product. Hawthorne and Yurkovich (1995) echo this call for a different way of evaluating care, as 'outcomes' do not address, "the unique relationship between the individual offering help and the individual in need of help.." (p. 1089). Seeing the individual as a whole person has become rather a meaningless concept due to gross over-use. However, the reduction of holistic need to a figure, a number, is a reality in health care provision. Individuals with learning disabilities have their psychological, spiritual, social, emotional and physical well-being reduced to a costed 'package' which can equally, be evaluated by numbers - number of community contacts, number of leisure pursuits undertaken etc. Wilkinson (1995) feels that these tools have become the focus within the health care arena and have displaced patient/client care as the focus of professionals' attention. In the same way in which the concept of 'care' may need a different cognitive framework to that used in the contemplation of 'cure', calls for more sensitive means of evaluating care are beginning to be heard. Barker et al. (1995) however, suggest that reflection upon the nature of nursing and of care constitutes self indulgent navel-gazing and that nurses are, "what, specifically, people-who-are-patients, need from them" (p. 389). Outcomes - patient outcomes - are the important factor. The article does not, however, address the issue of evaluating the differing frameworks through which patient outcome

might be addressed, or how one might measure these.

Perhaps we may reframe the threats to care outlined above as an awareness that the contexts within which caring takes place have an impact upon it, and changing social and economic values affect these contexts. In adopting this view we might, optimistically, view the cure/care difficulties and problems posed by continued reliance on positivistic frameworks as the results and, perhaps the remnants of an era whose paradigms are coming increasingly under question. The acceptance within nursing of multiple realities may also enable the profession to embrace the differences in professional history, professional socialisation and the work which practitioners do and to broaden the currently rather narrow focus of the exploration of care.

EMOTION IN CARE

Pam Smith (1992) introduced the concept of 'emotional labour' in her seminal exploration of nursing care. Recognising the emotional demands on nurses as they strive to maintain a supportive presence in the face of stress, anger, depression or simple tiredness, she conceptualises this process in terms of the work involved. Delivering the 'little things' that make all the difference to patients' experience requires, she suggests, labour and skill which is over and above simple functional competence as a nurse.

It was her reading of Hoschild's (1983) work with airline stewardesses and debt collectors which suggested the value of using Hoschild's 'emotional labour' as a template against which to consider nursing care. Hoschild defines emotional labour as : the induction or suppression of feeling in order to sustain an outward appearance that produces in others a sense of being

cared for in a convivial, safe place". Whilst the finer points of this definition may not apply to some nursing, nurses, as Smith demonstrates are undoubtedly involved in managing their emotions in this way in order to carry out their caring functions successfully.

The significance of this sociological analysis has only been taken up in a limited way so far in nurse education and research by Aldridge (1994) points out that the emotional labour of nursing receives little attention in terms of nurse education and research and suggests that this is part of the gender trap around emotion. Essentially, women are socialised from childhood to provide the emotional oil within the working of families and groups, and the extension of this to the expectation of meeting others' needs - of caring for dependants - becomes part of both societal and private expectation. This process is illustrated with clarity in Finch and Groves' (1983) reader and later, dramatically, in Goldhor-Lerner's (1993) work. This, again, serves to highlight the lack of attention to the concept of care within asylum nursing. The gender issues have been touched upon earlier. Within the custodial realm of the institution social distance was an essential part of the nurse's armoury (Goffman, 1960). However, the move to more normative relationships has raised the issue of the emotional component of care. Although not addressed in the literature the different gender and education balance may well provide a different focus for work in this area.

Many of the theorists cited at the beginning of this chapter include emotions or feelings as part of their definition or description of caring. Most, however, are imprecise about the content of this emotional component of care. Griffen (1983, from McKenna, 1993) for

instance, proposes, " two complementary aspects of the concept of caring" - activities and feelings. The former receives a paragraph of discussion, the latter a sentence. Hall (1990) and describes caring as an, "emotional or attachment state of the carer" (p.132) and Morse et al. (1990) suggests that this emotional attitude moves through stages of : attachment; assiduity; intimacy; and confirmation. The novice practitioner, or, indeed, the old hand, is given little guidance from theorists concerning the parameters of the relationship but opinions abound. Clarke and Wheeler (1992) identify an experience of , "giving oneself to another, creating friendship though trust, love and value for each other" (p. 1288). Dunlop (1986) frames this as a combination of closeness and distance. Benner and Wrubel (1988) write about "connection and concern" (p.1073) whilst Hawthorne and Yurkovich (1995) and Wilkinson (1995) also bring love into the frame as a major component of the caring relationship. Forrest's (1989) research indicates that nurses feel that one can care too little or too much , but, again, offers no boundaries for appropriate caring. One of the conflicts revealed in Menzies' (1960) work was that of emotional attachment v. detachment and this piece of research would seem to indicate that this central dilemma in caring remains one which individual nurses, often poorly prepared and supported, work through for themselves.

Barker et al. (1995) strike rather a cold tone in this debate, again removing the focus from the nurse and the emotional component of caring ("the almost narcissistic expression of interest nurse and the emotional componant of caring ("the almost narcissistic expression of interest in the experience of the use of self for therapeutic ends.."p. 395) and it would appear, would prefer a reversion to the 'technician' role for the nurse. It is interesting that Ward (cited in

Radsma, 1994) and Wilkinson (1995) both use the same point to support different arguments- the point that love cannot be bought. Ward, with echoes of Barker is reminding the reader that, " work is a paid commodity" and, therefore, not about emotional expression, whilst Wilkinson is illustrating the difficulties of introducing a market-style management into an essentially emotional relationship.

The research participants work within an environment where discussion of emotions about individual clients and about the labour of care is accepted albeit at a fairly superficial level. That emotion plays a part in their work is apparent in the way they talk to each other about the people for whom they care and about the way in which they approach this aspect of their jobs. Indeed, this work will suggest that the process of emotional labour in care work requires more rather than less emphasis and that there is value in looking beyond a sociological analysis to begin to explore the psychodynamics of the processes involved.

EMPATHY

That emotion does and should play a part in caring is a clear message from theory and research in nursing, and one element of this emotional labour which provides a focus for research and was a strong theme in this work, is empathy. "The concept of empathy in nursing is elusive and mysterious. Attempting to grasp it is an intellectual challenge; the concept keeps slipping out of the mind's grasp" (Pike, 1990, p. 235). The six years since Pike wrote this seem to have brought little additional purchase to the concept of empathy which continues to prove elusive. As with care, theorists suggest different definitions and descriptions of and different frameworks for viewing empathy.

Most theorists differentiate two types of empathy - trait and state. The first of these is described in the literature as : genotypic; natural or raw; ordinary; as 'feeling for' another. The latter is described as: phenotypic; clinical; professional; and as 'feeling into' (Astrom et al. , 1991). A theme which runs throughout the work is the necessity of separation from the other, after having 'felt into' his/her world, to form an effective empathic relationship. The borrowing of the other's emotion is seen as an intimate act, "of transposing oneself into the thinking, feeling and acting of another"(Kristjandottir, 1992 p. 136). Kalisch (cited in Pike, 1990) describes it as, "immersing oneself in others' emotion". This act of intimacy is, however, part of a process and is followed by reflection upon the emotional experience and the utilisation of insight/s gained to care for the client. "Empathy also requires a healthy psyche, flexible ego boundaries, and ready access to feelings" (Pike, 1990, p. 238).

This view of empathy as central to the emotional labour of caring raises many questions and those addressed below are particular to this piece of research. A large proportion of carers in this field are untrained , and yet empathy seems to demand high levels of interpersonal skill and self awareness. Perhaps, then, these carers are using trait empathy in the imagining of oneself into the emotional world of another. Hogan (1969) however, suggests that utilising trait rather than state empathy actually interferes with the therapeutic relationship as the carer over-identifies with the client and becomes over involved. Given the context within which the research participants work it would be difficult to gauge what constitutes over identification or over involvement. Many of the nurses in the study have cared for the same clients for many years, are intimately involved with their life events and decisions and provide high levels of

personal care. This point illustrates one of the difficulties mentioned earlier - the breadth of nursing. Much of the literature around core concepts in nursing is written by professionals whose contacts with clients is brief, during periods of illness and in the context of a return to 'normality'. As Kane and Kane (cited in Hall, 1990) point out, long term care is, "a perplexing, ill-defined area characterised by complexity and ambiguity.." (p.133). As this research illustrates, the complexity ranges around role, around purpose and around the nature of the caring relationship.

A second issue which I feel to be important in light of the client group of people with learning disabilities is the assumption that entry into another's emotional world can be assumed a possibility. Most of the clients for whom the research participants care have profound learning disabilities, some have additional sensory disabilities, most have little or no verbal communication and for many, life patterns and experiences have been shaped by years of living within large institutions. The importance of checking one's findings from forays into the other's emotional world is emphasised in the literature - Kalisch, (1973), Alligood, (1992) - and the difficulties presented for the carer for people with learning disabilities are evident. How then, can we 'know' the client's emotional world given the huge differences in perception, understanding and communication?

COSTS

Despite these difficulties many of the research participants did claim to understand the emotional precursors to self injurious behaviour in individuals and their relationships did reflect a high degree of emotional commitment, which theorists suggest (Morse et al., 1990,

Clarke and Wheeler, 1992) is the essence of the caring relationship. What, then, are the costs incurred by the carer on entering into this relationship? Parker's (1990) account of caring for someone in great physical pain illustrates that often the language and frameworks used within nursing fail to touch upon the reality of nurses' work, "...the language of rights, duties and obligations felt strangely alien to me....either I was not competent.. or I needed to find a different script.." (p.32). Similarly, the previous chapters began a discussion around different scripts, in care frameworks and ideologies for people with learning disabilities. We do not prepare carers, professional or otherwise for the emotional component of the work they undertake (Aldridge, 1994) and offer them little support despite their daily contact with damaged and damaging people.

That caring for another meets needs of one's own (Hall, 1990) is a proposition which, despite its resonance, has received little attention in nursing. This may be reflective of the historical and perhaps emotionally necessary pairing of nursing to concepts of self-sacrifice, of 'calling', of vocation and of selflessness. Whatever the emotional recompense, the emotional costs of caring are high. "The demands of nursing are large ones. The pains, risks, dangers encountered are sometimes great and cannot be experienced without personal cost" (Benner, cited in Dunlop, 1986, p. 668). Many of the feelings occasioned by caring which the literature in the field cited are those discovered in the course of this work. Aveline (cited in Hall, 1990) reports feelings of helplessness and hopelessness. Parker (1990) describes her own anxiety and frustrations, and Kohner (cited in Hall, 1990) describes feelings of loneliness, stress, depression, resentment, anger, grief and guilt in carers. In entering into the caring relationship

with a client, particularly if entering his / her emotional world, the nurse risks emotional harm him/herself. "Entering into a patient's world as if it were his own exposes the nurse to the possibility of pain, despair, anger, fear and helplessness" (Hall, 1990 p.238). The nurse's role is to offer comfort and help to the client and, thus, he/she needs to be able to withdraw from the emotion, to analyse it and to offer succour. This, in itself poses a risk for carers, as Aldridge, (1994) points out, - rejection of care is a rejection of the person also, for it is him/herself which is offered.

One effect of the emotional costs of caring which has been extensively researched, perhaps because it is perceived as financially costly, is burnout. Little work specific to carers for people with learning disability is available (Power, 1988), and research from other realms in nursing is used as a source of information, although some work particular to these carers is cited below. Generally, the cluster of behaviours and feelings which describe burnout include : emotional exhaustion; headaches; insomnia; low energy; low enthusiasm; apathy; desperation and raised levels of sick leave and absenteeism. Maher (cited in Firth et al. 1986) suggests, however, that it is loss of commitment which is central to burnout. Feelings of powerlessness feature in accounts of burnout (Astrom et al., 1991, Power, 1988) as does the concept of purpose/lessness.

Power's (1988) work addresses this issue directly, in a comparison of sources of stress and job satisfaction in hospice nurses and in those caring for people with learning disabilities. The features in the latter's work which cause increased levels of stress were found to be: "long

term exposure to a poor nursing environment, anti-social patient behaviour and purposelessness of therapeutic care" (p. 731). From the studies reviewed it again appeared important that workload was measured quantitatively and qualitatively as the factors which lead to breakdown in carers are complex. The balance between factors such as empathy (Astrom et al. 1990), accomplishment (Williams, 1989), engagement (Geissler, 1990), avoidance (Firth et al. 1986), professional depression, (Oswin, 1978), work overload (Power, 1988) and available support appears to influence the carers' ability to continue to care. The way in which these terms are used will obviously differ according to the nursing situation but research into whether sets of conditions which contribute to burnout (and to a positive attitude to work) in 'acute' as opposed to long term care are different is lacking.

COPING

Carers adopt defence mechanisms within particular relationships and as a broader coping strategy. Before suggesting, through an interpretation of the analysed data, how the carers in this study attempt to achieve this equilibrium, I will consider the emotional defences reported in the literature. Factors within the care situation will dictate the necessity for and nature of defence mechanisms in carers, the most obvious of which is the carer him/herself. Forrest's (1989) research suggests that carer's own experiences, self-appraisal and evaluation of the work will affect how well one cares and, as the earlier discussion on the costs of care indicate, prolonged contact with challenging client groups may well threaten these bases for effective practice. Anxiety in the carer also leads to the adoption of defensive measures (Menzies, 1960, Birch, 1975 and Revans cited in Gould, 1990). Factors in the individuals cared for are

also thought to be influential in the adoption of strategies for emotional defence in carers. As Stockwell's (1972) classic nursing study illustrated, some individual clients and groups prove more difficult for nurses to care for than others. The range of clients perceived as difficult is vast (which is interesting in itself), but both the disabled and people who are violent, or engage in behaviour difficult to understand feature largely in this field of literature (See Smith, 1992, Gould, 1990, Stockwell, 1972). Perceived frustration - with other nurses, with administration, the environment - all affect how openly nurses respond to clients and these factors are obviously particular to individual care situations. One factor which does seem consistent across different realms of nursing is that those who work closest to the client group are the most vulnerable and, therefore, the most likely to utilise mechanisms to defend themselves from emotional harm (Power, 1988, Firth et al., 1986). As the first part of this chapter explained those who work closest to the client group around whom this research is focused are largely untrained and unqualified workers. Thus those who are least prepared to manage the emotional components of care are exposed to the most difficult situations.

In both pieces of research by Astrom and colleagues (1990 and 1991) a high proportion of carers (45% in the 1991 study) reported the wish to change to other types of work : even a remote or fantasy escape for tomorrow appears to be one means of accepting today's work. Leaving - either care work altogether or the client group which forms the focus of any particular study - often features in the literature as a defensive/coping mechanism (Parker, 1990, Menzies, 1960). For professional nurses, moving from one client group to another may

be undesirable, as expertise built up over time may be lost. Further, for all paid carers, the demise of services which cater for a wide range of disabled people marks the end of an era in which nurses could move from one client group to another with ease. From the service user's perspective, having a constant stream of temporary carers may well exacerbate existent problems.

Oswin's (1978) work indicated that in avoiding harm through emotional involvement in care, nurses became conforming, rigid and institutionalised. Firth et al. (1986) concur with this, and their study suggests that nurses are aware of this process. In my study, the theme 'getting used to it' reflects this concept and for Williams (1989) it manifests as a, "defensive loss of empathy" (p. 170). Firth et al. (1986) describe this hardening in carers as those who are extrapunitive, whereas those who were intrapunitive are more likely to avoid problems, decisions or changes. Certainly, avoidance features in the literature on caring and its costs (Menzies, 1960, Power, 1988) and it is a theme to which we will return in chapter five. At one end of the scale of defence mechanisms, Benner and Wrubel, (1988) cite strategies such as humour and bravado, whilst, at the other, "elaborate self-protective manoeuvres" exist (p. 1075).

Menzies' (1960) seminal work explores the latter and will serve as an introduction to the interpretation of data in the final chapter of this study. Much of the literature which explores stress and coping in carers presents a picture of the nurse within the care situation who is aware of the pressures - emotional, and otherwise - upon him/her and utilising one or a

number of defences in order to enable him/her to continue to care. This rather uni-dimensional view pays insufficient attention, I would argue, to the extraordinarily complex emotional dynamic within the work undertaken. That nurses are aware of the facets of the emotional stresses and their responses to them is again simplifying the situation, the carer, the client and their relationship. Further I would suggest that the carer's responses are vibrant, changing and largely unconscious, shaped by his/her needs, memories and aspirations.

This review of the nature of care in nursing has moved us away from the realms within which this chapter began - that of the assumptions of certainties of knowledge which nursing's association with medicine has previously promoted. The medical model reflected a safe, routinised world, within which a series of 'givens' removed much of the uncertainty in working with people in distress/discomfort. Isobel Menzies (1960, to whom I shall return) suggests how the rituals within nursing serve to contain individual nurse's anxieties over interactions, this being a reflection of how the medical model contained anxieties on a much larger scale. The chapter has also highlighted how the history of nursing and nurses for people with learning disabilities has been subsumed into the wider history of nursing. Thus uncomfortable absorption has left many areas of interest in care for people with learning disabilities unaddressed - or, rather, addressed through the lens of 'general/adult' care - a largely inappropriate medium. This piece of research addresses one area within this different ground - that of caring on long term basis for people with learning disabilities who are self injurious.

Differences notwithstanding, it is against this changing epistemological and professional background that this research is undertaken and, in accordance with the issues above, the research attempts to elicit, describe and interpret the experiences and emotional coping mechanisms of nurses caring for self-injurious, learning disabled people.

CHAPTER FOUR

METHODOLOGY

THE STORY OF THE RESEARCH

CHAPTER FOUR

METHODOLOGY

The initial form of the enquiry, "How do nurses cope emotionally with caring for learning disabled, self injurious people?" presupposed some answers which would, perhaps, tell a straightforward tale of shifts, in a neat, chronological order from the beginning of each participant's work to the present. However, both 'that which-is-illuminated' and the process of illumination are in a continuing dialogue, dependent upon the stance of the researcher. To address the latter, the epistemological stance chosen will directly affect the fidelity and coherence of the explanatory framework offered. Reflection upon this relationship calls for the maintenance of a tension between the creation of the material and the analysis of that act of creation. To address the former, my feelings about the issue of concern here (caring for people who self injure), about the research participants, about what they say, requires a reflective awareness of my contribution to the mutually created and individually perceived reality.

Whilst imagined as a work with a distinct beginning, middle and end, the piece has changed shape and 'ending' has proved difficult. "Events and conversations of the past are forever being reinterpreted in light of new understandings and continuing dialogue with the studied" (Van Maanen, 1988, p. 118). This chapter will attempt to uncover and explore some of the issues involved in this complexity. The first part of this chapter focuses on the research process. It tells the story of the approach to the work, and the undertaking and completion of it. In this account, I try to convey something not only of the work itself but also of the feelings which various stages of the work evoked. Commentary on the theoretical issues raised follow in the second part of the chapter. This latter part of the chapter will address broad methodological issues : the emergence of qualitative research methods; issues of rigour; the place and contribution of the researcher within the work.

THE STORY OF THE RESEARCH

THE RESEARCH SETTING

"The act of enquiry begins with issues and/or concerns of participants and then unfolds through a dialectic of interaction, analysis, critique, reiteration, reanalysis, and so on that eventually leads to ...construction of a case" (Schwandt, 1994, p. 128). This section of the chapter attempts to relate how these processes emerged during this research.

Informal Access

The first stage in the work was to find a group of nurses who would be willing to participate in the work, given the nature and length of the involvement necessary. My job involves contact with nurses who work with the client group in question and this facilitated access to the group of carers in whom I was interested. My professional contact with service providers brings me mainly into contact with local N.H.S. Trust care facilities and so two residential homes from within the range of facilities were chosen. Local day services were not really a viable option for this work as they exclude many people with challenging behaviour - the client group of interest to me. The homes chosen provided a range of carers and experiences as the description below will indicate.

One of these homes is within a hospital for people with learning disabilities which has been established for sixty years. At the time the research started the process of moving clients out of the institution and into smaller, community based homes had been underway for about ten years. The home constituted the lower (later moving to the upper) floor of a villa within the hospital. This building has always been used for 'challenging' people and carries a distinct

history which has become part of the institution's mythology. Meals are provided by a central catering service and regenerated in the kitchen. Domestic tasks are undertaken by staff other than nurses and a housekeeper is responsible for the provision of toiletries, care of clothing etc. The range of difficulties faced by the women are those concomitant with severe learning disabilities in terms of living skills, but more pertinently, all of the women have some degree of challenging behaviour. These include all forms of aggression, destructive behaviour, faeces - smearing, and, of course, self injurious behaviour.

Currently, this home caters specifically for women with behaviour which may challenge who it was considered difficult to place in the community. To date all of these women live within the institution and in fact they spend little time outside the hospital. The staff who work in this home are self selecting and, on the whole, enjoy working with this client group. Many of the nurses and clients have known each other for many years, as carers have worked within the hospital and many of the clients had spent a large proportion of their lives there. At the beginning of the research the physical environment was poor, with the furnishings and fittings being those typical of an institution. Attempts to augment the environment by the introduction of softer furnishing were stymied by the destructive behaviours of some of the women who live there. The structure of the building allows little privacy.

Three care staff per shift gave care to the twelve clients and, owing to the perceived nature of the clients' needs, one of these staff remained in the lounge with the clients at all times. However, due to problems of long and short term sickness the women were frequently cared for by 'bank' staff who may not have had any previous knowledge of the individuals and their needs. The permanent members of staff covered as many shifts as possible between them, with all of the consequent problems of long hours and infrequent days off.

Toward the end of the second round of interviews, there was a marked change in the physical and emotional environment at the home. As a result of the death of one of the clients and the resulting enquiry, two of the clients were moved to other hospital accommodation; the staffing levels were increased dramatically; and the staff opted to work twelve hour shifts, thus providing much improved continuity of care. In effect, by the end of the study some of the women perceived as the most challenging received one to one care. The effect this had upon the interviews was to reduce the amount of time spent on 'horror tales' about any individual and to make focusing on the participant him/herself easier. Over the course of the research there were more staff changes than at the other home. Only three of the original participants were 'lost', the others being moved within the Trust, where I could follow them up. As the data analysis chapter will reveal, these moves were seen by the carers as temporary, 'their' client group continuing to be people with learning disabilities who challenge others.

Although as the table on p.96 shows the staff at this home represent a good spread of age and experience, the other home was chosen to ensure a range of carers. Some of the carers from the first home had worked in and around the hospital for some time and all now worked within the institutional culture. Of the carers in the second home, many were recruited directly to it and so had not worked within a hospital setting. This home is a large house in a middle class, residential area of town and is a home for people who have sensory as well as learning disabilities. The home has an excellent reputation among local service providers for being relaxed, progressive and well staffed. A greater variety of client need is apparent here, from one individual who needs total care to those who are almost fully independent within this setting. The physical environment is more pleasing and allows much more space for both clients and staff and over the course of the research much less change was experienced here. During the

second round of interviews, a change in the management structure took place with the sister leaving and a system of team nursing replacing the former hierarchical management. Given the egalitarian relationship within the staff team this had little impact on individuals' experience of their work, apart from one of the younger registered nurses who did feel the weight of increased responsibility. Of this group, two were 'lost' owing to moves. Table two on the following page gives details of the research participants.

I felt that early contacts with and the request for carers to take part in the research needed to be approached with care. I felt they needed to be aware of the commitment they were being asked to adopt and to understand the nature of the research process. I also wanted the aim of the work - improvements in support and consequently in care - to be clear. Initial contact with the nurses consisted of meeting with them singly or in small groups to outline the research and to ask whether they would be willing to take part in the work. One difficulty emphasised in the field notes at this stage was gauging the level of understanding of the process by the staff involved. In brief, the original participants came from a wide educational and professional spectrum : nine nurses registered in the field of learning disability; two in the field of general nursing ; the remainder non-professional staff of varying educational backgrounds, from university dropouts to those with no formal academic qualifications. The vast majority of them had no knowledge of research at all and so trying to balance the amount of information which would be fully informative as opposed to overwhelming was difficult. In effect, I found I was pitching quite differently with many of the staff but felt reasonably confident that they all appreciated : the aims of the research; why I was doing it; what their involvement would be ; and lastly, that their thoughts, words and ideas would remain their own.

All of the staff in the two homes agreed to participate in the work indeed, seemed pleased to do

so - for which I am grateful. I was also somewhat surprised by the fact that all of the carers were willing to be involved. In retrospect, I feel that the work may have had some 'glamour' attached to it - attention to carers is rare. Despite my attempts to the contrary, however, it became clear as the research progressed that for many of the research participants the purpose of the interviews was rather vague, despite reiteration. To some extent, I feel that my work was interpreted as 'research', which was seen as sufficient explanation in itself. This did cause me some consternation at the beginning of the interview process as I had thought the research participants needed a clear picture of the whole of the work. However, it soon became apparent that details around (for instance) data analysis were neither meaningful or relevant to them and insight into finer detail was not a pre-requisite for participation.

Participants, by place of work :

HOME A

Skill mix :

Registered Nurses for the Learning Disabled	4
Registered General Nurses	1
Care Assistants	8

Gender :

Men	5 (1 R.N.L.D.)
Women	7 (3 R.N.L.D., 1 R.G.N.)

Age Range : 19 - mid-fifties

Experience : Few weeks - 15 years

3 staff left this work during the gap between the first and second round of interviews and were replaced by two new staff. Three more staff moved employment within the organisation and were followed up in their new posts. Near the end of the second round of interviews five new care assistants were employed, but were not included in the study.

HOME B :

Skill Mix :

Registered Nurses for the Learning Disabled	5
Registered General Nurses	1
Care Assistants	10
Gender :	
Men	6
Women	10
Age Range :	mid twenties-mid fifties
Experience :	1 year - 20+ years

Two of these staff left this type of employment after the first round of interviews and were not replaced at a time suitable for inclusion in the work.

One problem common to many nurse researchers became apparent at this first tentative enquiry - that of role differentiation. I had worked with many of the nurses in the study for many years, in both an educational and a clinical capacity. For these people, the task of differentiating my research role from my teaching role did not appear to present a difficulty as I was identified as a person and not a role. However, for others, particularly the newer staff, the difference in aim and role had to be reiterated many times. This was particularly important in the early stages, as I did not want the staff to feel that the research was part of my job and any accompanying sense of obligation to take part.

Stephonson (cited in Reid, 1991) raises an issue common in nursing research - that of the credibility of the researcher. In some ways I had the opposite problem, as my credentials as a nurse were not in question, but I was now asking the staff to see me outside that role. Jones (cited in Allan and Skinner, 1991) suggests that there are many issues to be raised within the research field around the researcher's class, status and gender. Although attempting to engage the participants in an egalitarian conversation, I was aware at the beginning of the interviews that the participants expected me to be 'in control' : as we settled into the conversational form,

this expectation disappeared. This can be seen (literally) in the transcripts of the interviews, particularly the first round, where my contributions tend to be in the form of prompts or contributions rather than questions as the interviews progress. As an example, in one interview my early contributions to the conversation were: "So you'd been here as a volunteer before you came to work here. Do you think that helped you to know about the work?" and "So why do you think that the ear banging and the head banging are from different causes.. about different things?" ; and my later contributions consisted largely of prompts - "Hmm..." and "Uh-huh...". One means of overcoming this difficulty of role differentiation immediately presented itself. Since the research was to be undertaken in my own time I would be seeing the staff largely in the evenings or at weekends, which would serve to make some differentiation. Also, my dress would serve to emphasise this difference as I dressed far more casually for the interviews than for 'work'. Also, at these meetings, the preamble to interviews always contained a reiteration of the purpose and nature of the work which again helped to differentiate 'teacher' from 'researcher'. The differentiation of the two roles was an issue of which I also needed to be aware. I occasionally felt an imminent lapse into 'teacher' mode which for the most part I managed to stave off.

Formal Access

Although the research did not include direct involvement of clients, because it was to include health service staff the research proposal was put before an ethics committee and discussed with the Nurse Advisor and General Manager. No difficulties were encountered and both service staff representatives were extremely encouraging. Indeed, support from service colleagues of all professional backgrounds has been a prop throughout the entire process. I felt it important to discuss the research with the participants before they heard of it from their

managers as I did not want the staff to feel obliged to take part. Other researchers (see Reid, 1991) have commented on this, and in the case of this research, where participants are being asked to share their emotional lives, any hint of coercion would have been counter-productive. The work began with a substantive literature review - the material for Chapter 2 - and with reading around method, which constitutes the latter part of this chapter. The former proved to be extremely useful, although not, perhaps, in the way initially supposed. The material served to provide a context for the research process - a clear picture of the theoretical and ideological backdrops against which this research takes place. From the perspective of writing the chapter, this was a stage with which I felt very comfortable, as I am familiar with the kinds of skills involved and thus did not feel anxious or threatened by this process.

The next stage, however, involved skills with which I was far less familiar and at the time I was undertaking the interviews, I felt that the viability of the whole work hinged on the "success" of the interview process. Consequently, this stage was approached with some trepidation.

DATA COLLECTION

The data was collected by means of two rounds of interviews: the first unstructured, the second based upon the themes emerging from the first. All of the interviews were held at the respondent's workplace, and all were preceded and usually followed by a cup of coffee and a general chat with the respondent. This 'non-research' conversation and sharing of a drink constituted a warming up and cooling down period, so that the respondent felt neither rushed at the beginning nor abandoned at the end of an interaction.

Interviewing - Round One

The question, essentially, for the first round of interviews was 'what are the emotional issues involved in caring for this client group?' All of these interviews started with some personal/professional history which would be useful and also ease us into conversation and then focused more specifically on the question. Chenitz (from Chenitz and Swanson, 1980) points out that the researcher needs conversational grace in order to begin, maintain and end conversations with participants and also the sensitivity to be aware of group rules and norms.

The only guidelines I adopted for these first interview were that I would raise the following areas in relation to self-injurious behaviour. Firstly, how the respondent felt about it when s/he had first seen it and secondly whether those emotions had changed. In most of the interviews it was only the first of these which needed to be asked directly, the latter emerging in the course of the conversation.

As the interviews occurred in the participant's workplace and so the demands of the interview would necessarily be secondary to the demands of the client group. Consequently, on a few occasions, interviews were interrupted by the participant being called away or by clients coming into the interview room. These occasions touched upon another issue raised by Chenitz (op. cit.) which is the difficulty posed by the clinician as researcher. When clients were behaving in ways which required intervention, should I switch off the recorder, sit back and wait or become involved? In all but one incident, my involvement would have been superfluous and in the situation in which I did intervene two people were clearly needed to prevent the learning disabled woman from harming herself. As a corollary to this, during the course of conversation, nurses often asked for confirmation/affirmation of their beliefs or opinions. Oakley (1986)

discusses some of the difficulties inherent in this situation : essentially and in keeping with her thought, I answered the questions as honestly and tactfully as possible. For example, in discussing a particular individual who engages in self injurious behaviour, one participant asked, towards the end of this part of the conversation :

"Do you think that A's Dad is responsible for all that ?

(meaning headbanging) I mean, do you think it's his
fault?"

To which I replied (a little pompously) :

" I certainly feel that early childhood experiences have
an impact on adult behaviour in all of us... and I
don't see why that should be any different for
people with disabilities..."

At these moments, I felt the teacher/researcher divide most acutely, as I did not want to be perceived as adopting the role of an 'authority', yet did not wish to appear to be "fobbing off" the respondent.

During these first interviews I was astonished that people were so ready to talk to me about their work and their feelings about caring for self injurious clients. As a consequence in the early interviews I found it quite difficult to curtail areas of conversation which did not ultimately contribute to addressing the research question. One example which springs to mind is that during the early stages of the first interviews, in order to encourage the participants to relax and to accustom themselves to the environment and to the recorder, I asked them to explore possible causes of self injury. This proved to be a rich vein of opinion but yielded little directly in terms of the emotional labour of care. Further, having stressed the non-directiveness

of my approach for these first interviews, I was, perhaps, too non-directive (!) in striving to prove my sincerity. Chenitz (1980) suggests that the neophyte researcher maybe tempted to form a focus for the work too soon, and suggests that he/she 'rides out' this temptation. During the first round of interviews, I rode out this temptation - to excess - but felt more confident to set parameters during the second round.

Finally in discussion of this round of interviews I also sensed and was told, that many of the participants valued the opportunity to talk to someone about how they felt and to be challenged on their assumptions. It seemed churlish to invite this response and then to stifle it. Some feminist writers (Oakley, 1986, Finch, 1984) have raised issues around the possibly exploitative nature of the research process. Certainly, the in offering a sympathetic and insightful 'ear' I was aware of the relief of some of the research participants in being able to discuss their feelings. Indeed, Finch (1984) suggests that in interviewing women, one only needs to be a woman oneself to invite confidences. Inevitably the perception of the interview held by the researcher and that held by the participant will be different and consequently the scope for exploitation is wide. Another dimension here is the line between research and therapy - particularly when dealing with emotion. Engaging in research as a dynamic process rather than as a recipe means being alive to and reflecting on these issues, rather than working to some kind of etiquette guide. The uncovering of dis-ease has been the fundamental finding of the research - that it is this emotional tautness which enables people to care. Thus, the knowing and the known again parallel each other.

Each interview was recorded and then transcribed. Other methods of recording the pertinent parts of the interviews are possible, but I decided that audio recording was probably the most

unobtrusive and thorough. As a teacher, I have spent many years talking to the tops of the heads of people taking notes, and do appreciate how disconcerting this can be, even to one who speaks for a living. The verbatim transcription of conversation renders huge amounts of data and perhaps offers the opportunity for reflection which could be lost with less direct and more researcher- dependent forms of capturing the participants' thoughts. Further, in the interview situations outlined here, I felt that the withdrawal of my immediate and obvious attention (in order to take notes) might interrupt the flow of conversation, as well as appearing threatening to the participants. The tape recorder used was small and unobtrusive, and after some initial embarrassment, did not appear to cause any difficulties to the participants although it was a cause of continuing anxiety to me.

Transcription

Transcription of the material took place as soon after the interview as possible, with a copy of any field notes attached to the transcription. I transcribed all of the data myself for two reasons: firstly, a practical issue of expense - I could not afford to pay someone to transcribe the tapes. And secondly, I felt that I had no way of knowing what was to prove important and was, even in the second round of interviews, anxious that I might miss some startling revelation. This process of transcription proved to be a task which brought both misery and joy. It is almost impossible to describe the tedium of transcribing pages of material, which (due to the conflicts discussed above) appeared to have little relevance to the research question. However, this tedium was also tinged with the anticipation of finding a rich vein of pertinent conversation. This was balanced by the excitement of hearing and seeing much rich, emotional data and feeling the emergence of codes and categories - an exercise which, as discussed below, it is difficult to separate from the 'analysis' period.

Transcribing the material also brought an intimacy with it which I feel would have been difficult to gain in any other way. Listening - often repeatedly - to the respondents words (and unfortunately my own) and the physical act of writing and seeing them facilitated a close contact with the pattern and flow of each interview. Ideas for codes and categories began to emerge during this process.

Analysis Of The Round One Data

A grounded theory approach was used in the analysis of this data - see the diagram on p.111. At this stage level one coding led to the evolution of a number of themes from the data. The process of working the data for themes was one of the most exciting stages of the research but also the most anxiety provoking as I felt that a failure to raise interesting and coherent material would indicate a failure of the whole enterprise. I found the engagement in the analysis enjoyable as it involved attention to method, reliance on memory and creativity. The work was done by putting copies (two 'working versions and a third to capture ideas which did 'work') of the transcribed interviews into lever arch files, with a blank sheet interspersed between each single sided leaf. As each contribution (i.e. chunk of speech from the research participants) was read, issues pertinent to the research topic were highlighted in one of many coloured highlighters. The blank page opposite was used for notes - often just one or two of the words from the data which served as a working 'title' for the theme plus my thoughts about the contribution. Material from the themes was then physically grouped together to give a picture of the range, size and coherence of the theme.

Once the transcripts had been worked through the themes which had emerged were compared

to and against each other and condensed to separate themes. Although this process can be described easily and quickly, this preliminary analysis took many months of detailed work : schemes for coding were tried and abandoned; many copies of the data were used in the attempt at grouping and re-grouping of the material. The constant comparison and the search for ideas which would fit comfortably with the emerging themes proved addictive - a heady mixture of anticipation, excitement and anxiety (see Garner, 1991). However, the final emergence of the themes gave an enormous sense of satisfaction. The first 'working' of the data yielded a huge number of potential themes and relinquishing these proved painful. Some of these were not specifically related to emotional labour. Others were related to emotion, but not to the care situation. Coding and sorting of categories and memos frequently revealed that what had initially seemed separate categories were, in fact, aspects of the same idea. At this stage, the appearance of discrepant ideas within categories worried me very much, but the interpretation of the analysed data has indicated the importance of attention even to seemingly frustrating and incongruent detail of the data. Garner's (1991) technique of avoidance came heavily into play at this stage and I was reluctant to move on in the research process. Once they appeared satisfactory, a copy of the set of themes was sent to each research participant prior to the level two interviewing. Each theme was briefly described with the request that some further thought be given to them prior to the next interview.

Interviewing - Round Two

Thus the analysed data from the first round of interviews formed the focus of discussion for the second and each participant was given a copy of their transcribed interview. Reactions varied on looking at these, reactions varies. Some participants were fascinated by 'seeing their words': others did not want to read through the transcript. None, however, asked for any change to the

transcribed material and this surprised me as many participants responded to seeing their words with comments like, "I didn't say that, did I?" or "That sounds awful...". I was also relieved that no omissions were required as this might have changed the tone or focus of the work.

The second round of interviews – particularly the early ones – demonstrated to me the very different perceptions that I and the participants held of the work. For me, the work was alive and humming in my head. Some of them could barely recall the first interview. Whilst I obviously understood this at a practical level, it did cause me some difficulties as in fidelity to my epistemological stance I had a vague notion of the research participants feeling more ownership and participation in the work than was evident. This feeling abated as my understanding of a constructivist approach developed through the remaining stages of the research process.

The themes which had emerged were briefly described and the conversations ranged around these. The first round interviews varied considerably in length. One participant, (referred to as 'the nightmare' in the fieldnotes) who is an extremely shy young man at the best of times, was rendered virtually monosyllabic by the interview situation. Despite my best efforts, he could not engage in conversation and this interview ground to a halt after about fifteen minutes. The transcription looks like a 'negative' of the others, with my contributions becoming longer as his silences become more profound. The conversations of the other participants generally lasted thirty to forty minutes, the longest running for about fifty. This last was one of the earlier interviews and, as suggested above, contained much material which was not directly relevant. The second round interviews were shorter (even for 'the nightmare') and lasted, on average, fifteen to thirty minutes. Initially in this round I was worried by this but felt the change partly was due to the nature of the discussion and partly due to my increased confidence.

Some of the material from these interviews proved a repetition of earlier conversations owing, partly, to the time lapse (over a year). Also, many of the participants felt they had little fresh material to add, frequently using phrases like, "yes.. it's that, isn't it?" and "well, that's it..." However, some important fine tuning of themes occurred during this second round of interviews. Themes which had covered a lot of emotional ground (e.g. anger) were discussed in more detail and refinements in some of the other themes also formed a focus for conversation. The research participants who had either read their transcript or who could remember the earlier conversation took the opportunity to clarify some points and some discrepant, rather than negative (Garner, 1991) material did emerge. I also felt more confident to challenge the interviewees at this stage and did press them on issues which seemed important. This was rather a delicate manoeuvre and had to be played very much by ear, according to the participant's character, mood and the relationship established.

Data Analysis - Round Two

The transcription and analysis of these interviews followed the same pattern as for the round one interviews. Whilst the framework for the first round was envisaged as a guide, it was fact not substantially revised. The more detailed coding undertaken and memoing (see section below) meant that the data could be organised into the format presented in the next chapter.

Field Notes

I also used field notes as a means of recording my observations and impressions about the research process. These consisted of comments on the data collection, the emotional tone of the interview, any difficulties encountered and how I felt the interview had gone. In other stages of

the research, they are comments on the progress (or otherwise) of the work, theoretical memos and notes on how I feel about the project generally. A few examples may help to illustrate the uses of these. One example pertinent to this stage followed a difficult interview with the young man mentioned above who remained almost monosyllabic throughout. I found this experience frustrating and somewhat embarrassing and the field note following this interview read :

"Jones (from Allan and Skinner, 91) - 'even experienced researchers may have difficulty in establishing rapport'. How are they at pulling teeth?"

And following an interview with a care assistant, who had been very positive in her opinions and certain of her role with people with disabilities :

"Felt really irritated with E during this interview. Couldn't pin this down at the time, because, per se, it went well. On reflection, perhaps she reminds me rather of myself a few years ago - such certainty."

If we may view reflective research as 'telling a story about ourselves', (Steier, 1991) then the field notes provide sketchy reminders of the direction of the tale. Spradley (cited in Kirk and Miller, 1986) suggests four types of field notes : the condensed account; the expanded account; the diary; and a running record of analysis and interpretation. My notes, which are sparse and thin, were part diary/part analysis and would not fit into Spradley's formula. They would, however, fit Kirk and Miller's (1986) description "fieldnotes are rarely published or distributed (as) they tend to be entirely unintelligible to anyone who does not take for granted the same things as ... the fieldworker... qualitative researchers commonly find their own earlier notes ambiguous or incomprehensible.." (p. 39).

DATA ANALYSIS - Discussion

Grounded Theory

As a data analysis method, grounded theory was made known via the publication of 'The Discovery of Grounded Theory' (Glaser and Strauss) in 1967 and is now widely used. Strauss and Corbin (1990) write that a grounded theory is, "discovered , developed and provisionally verified through systematic data collection and analysis of data pertaining to that phenomenon" (p.23). It shares with other methods an emphasis on interpretation and consequently many of the questions raised around the role of the researcher, addressed above. Strauss and Corbin (1994) argue that it differs in that the aim is theory (usually substantive theory) development. Some confusion between data and understanding / interpretation is apparent when theorists suggest that the idea of analysis should be rejected and the data allowed to speak for itself. "Boas... was an ethnographic nudist, preferring to display, not analyse, his collections of cultural materials" (Van Maanen, 1988, p.53). Given the epistemological stance adopted here I would support Hirsch (cited in Kirk and Miller, 1986) who suggests that data has already been filtered through the researcher's world-set and assumptions and thus, there is no 'raw' data. Further illumination and explanation need to be worked and drawn from the "heavy glop of material" (Van Maanen, 1988, p. 118) rather than hoping that they will just shine through which, "despite the student's prayers ,"(Garner, 1991) they do not.

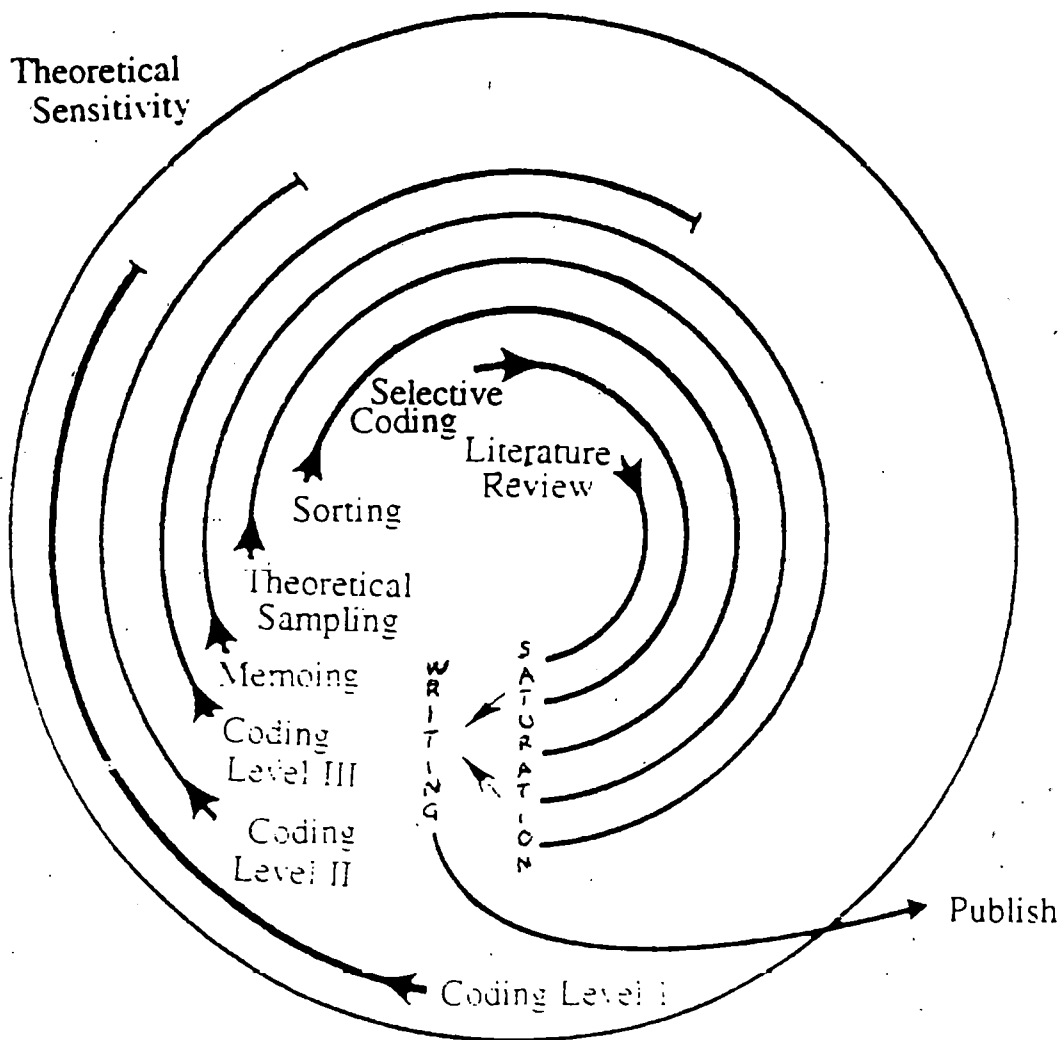
Silverman (1993) states that it is analysis which is central to evaluating qualitative research and many forms of data analysis exist. Essentially, analysis is the refining and reorganising of data so that it explains and illuminates the research field. The theoretical perspective and world view

which the researcher holds are as crucial here as in the data collection, as the raw data is filtered through his/her assumptions in order to create an explanatory framework (Van Maanen, 1988). Morse (1994) suggests that one reason for the low esteem in which qualitative research is held in some academic circles is the lack of description of what actually happens in analysis and, in order to pre-empt this criticism, the method has been described above. "The unconventionality (of the work) flows from the interest of qualitative researchers in the yet undefined" (Van Maanen et al., 1982). In attempting to be clear about the data analysis undertaken, I do not wish to give the appearance of a 'recipe book' approach - the data analysis proved a complex, long and sophisticated process.

The approach taken and described originally was that outlined by Sally Hutchinson (from Munhall and Oiler, 1986 : see Fig. 2 over). The thrust of the approach Hutchinson suggests is the disclosure of a 'core variable', which is the essential element of a theory, which provides explanation, illumination, integration of the data - basic psychological processes are one type of core variable; social structural processes are another.

Coding, which takes place at three levels, is simultaneous with data collection. This circular concept - that the data collected influences the search for further data - is reflected in the two rounds of interviewing in the work. Level I coding involves sorting the data under headings which describe content themes which run throughout. This process was described in the account of the analysis of data from the round one interviews. Hutchinson (from Munhall and Oiler 1986) herself suggests using (as have other researchers) words and phrases coined by the participants themselves as headings for these codes and this proved to be a useful and valuable technique as it kept the research themes and codes live and gave a sense of shared ownership.

Level II coding



HUTCHINSON, 1986

results from reworking and condensing/discarding some of the level I codes, into categories which occurred in tandem with the level two coding following on from the second round of interviews and at the literature review. Level III coding involves a combination of the worked data with appropriate theory - both academic and clinical - to verify the findings.

Memoing is a process which continues throughout the whole of the research process, alongside coding. It involves the linking of ideas and connections which occur to the researcher, to particular codes and categories. The memoing which I did formed part of the field notes which were taken throughout the process. Similarly, the constant reworking of the data necessary for a grounded approach facilitates this process of patterning and re-patterning of ideas (Glaser and Strauss, 1967).

It is from the sorting of memos and categories which the theory emerges. Formal theory and substantive theory are differentiated: the former address a conceptual level of enquiry, whilst the latter are pertinent to a more specific field. The question of whether one can set out to provide one (or the other) of these is a question which seems at odds with the method, yet influenced by the scope and setting of the piece of work. Theoretical sampling consists of the comparison of codes against emerging theory which may give pointers for further data collection. Theoretical sampling illustrates two issues. The first of these is that the categories which have emerged from coding are saturated - that is, the codes and memos which occur fit into these categories. Secondly, the significant variables become apparent through this process of comparison to theory. I found, as discussed further below, that this process became part of the coding/memoing pattern which continues throughout the work rather than as a separate step or stage. Sorting involved examining the codes in more detail in order to write up

the work. Memos and codes were sorted and separated and then explored in terms of the theoretical constructs one brings to bear on the work.

The whole analytical process proved not to be as easily compartmentalised as I had, from the literature, expected it to be. Whilst the three levels of coding are presented as overlapping, it proved difficult to prevent these from collapsing together, as working constantly with the data (collecting, transcribing, reviewing) led to multiple layers of analysis. Similarly, there was a huge overlap between memoing and theoretical sampling - the process of constant comparison of codes against thoughts as they emerged curtailed the need for a separate stage. Morse (1994) suggests an alternative way of viewing the process, of moving through four stages : firstly, comprehending, which is learning about the research setting and the people. Morse includes coding in this stage. Secondly, synthesising, which is the drawing out of patterns and theorising, which links the research findings to, "the greater body of knowledge"(p. 32). The final stage is forging connections between the emerging theory and established theory and to the work of other researchers. The similarities with the approach used in this work are clear, but despite her stated intention, Morse does not indicate the details of the process involved.

The interpretation of the research data became clear during the process of understanding - via analysis - the experiences of the research participants and my experience of the research process. The themes and categories the tones and colours of the work all pointed toward the substantive theory which is presented in the final chapter of this work. Contemplating this process of 'analysis leading to interpretation' also caused me anxiety and raised the (by now) familiar worries about my own ability to manage the process and to contain and address the issues raised. This step proved in some ways easier and others harder than anticipated. The

outline of the theory - of ambivalence and of tension - stood out clearly from the data analysis. However, forming an interpretative frame which would fit the data and prove useful and workable in practice proved a more difficult task. Various interpretative frameworks were tried in the attempt and much emotional energy expended in these attempts. The final theory which did emerge was, perhaps, the least ambitious of these attempts and its simplicity may account for its success.

THE LITERATURE REVIEW

Many grounded theorists suggest that it is at this point that the literature review takes place, suggesting that this late review of pertinent literature in order to avoid importing alien frameworks into the data analysis. Whilst the literature review of the issue of caring in nursing was, indeed, postponed until after the data collection and analysis, it has been presented in chapter three in this account in order to avoid confusion of the issues emerging from the work. I approached this process with mixed feelings. At one level, I was engaging in an activity which created much less anxiety for me than had the unknown and (personally) uncharted waters of the previous stages in the research. At a different level, I was concerned that too much or too little congruence with my own findings might prove damaging. As the review in chapter three has revealed, the literature available in the field was written (largely) for and by those involved in the care of people who are physically ill. Whilst not denying the undoubted overlap of skills and knowledge the nature of the work undertaken in this arena and in the realm of care for people with learning disabilities is hugely disparate and thus much of the literature does not address issues of longer term care. It particularly does not address the issues of caring long term for people who may present challenges to the emotional equanimity with which we feel comfortable. This research has begun the process of addressing that deficit. Certainly, the

theory which has emerged from the data is at odds with much current thought on the concept of care in nursing, so perhaps delaying the literature review until this point facilitated this freedom of thought. This delay did cause me some discomfort as it ran counter to my previous experiences of research and of academic undertaking. The data analysis and interpretation felt rather 'risky' as I had, at this stage, no theoretical framework into which to tie it or against which to compare it.

WRITING UP

The Final Frontier

Van Maanen (1988) differentiates three types of ethnographic tale: the realist; the confessional; and the interpretist. The first of these represents the 'researcher as conduit for reality' approach to qualitative research and is written in the "dialectic deadpan" (Clarke cited by Van Maanen, 1988). The focus of this work is the known and it is apparently written from some lofty, objective viewpoint. The second of these is produced to support realist tales. They focus on the presence of the researcher, but "it is necessarily a blurred account, combining a partial description of the culture alongside an equally partial description of the fieldwork experience itself" (Van Maanen, 1988, p. 91). The last of these focuses on the process of research and uses dramatic control of the text for impact. Again, interpretist tales are used to support realist tales. The style of these works has led to the question being raised of the line between literature and research, by many commentators (Hammersley, 1992, Garner, 1991): the essential difference lying in the accessibility of reasoning from data to theory and in demonstrating the use of available materials. Given the constructionist stance taken in the work, the writing up of the work becomes part of that construction. "What one writes is what happened and what was learned" (Garner, 1991). The whole of the work addresses those issues, by providing rationale,

context, history and a description of the research. This chapter and the next indicate and illuminate the path toward the emergent theory. Writing up is a task which is (again) postponed by many researchers as it brings one to face the questions of when and how to stop. Given the on-going nature of the dialogue between the researcher, the participants and the method, how can one know where to end? This tale aims to present the process and emerging theory as reflections of each other and perhaps that point has been reached. "We know that our analysis is not finished, only over" (Van Maanen, 1988, p. 120).

Before presenting the research findings, I think it would be useful to draw together the issues raised in the previous chapter on the nature of knowledge in nursing and to illuminate the links between those issues and the research undertaken. The remainder of this chapter will also attempt to address some of the broader methodological issues in the nature of the research process undertaken.

METHODOLOGY

Why Qualitative Research?

Strauss and Corbin (1990) suggest that people use qualitative research methods because of their philosophical orientation and the nature of the research problem. The latter was also undoubtedly an influencing factor at the outset of the project and subsequently, the sophistication and sensitivity of the method required have become apparent as the work progressed. The paradigm shift in nursing explored in the previous chapter calls for research methods which will reflect the move to a model which echoes the holistic, interactive nature of nursing (Munhall and Oiler, 1986). This approach, however, is not un-scientific : "It is an

increasingly accepted view that work becomes scientific by adopting methods of study appropriate to its subject matter" (Silverman, 1993, p. 144).

However, much of the qualitative research and the writing about research in nursing assumes what Hammersley (1992) calls naive realism. It assumes that one can capture another's reality without influencing it oneself. Porter (1993) cites Kath Melia's (1983) work entitled, "Tell It As It Is", as an example of this. This chapter will suggest that the work in fact represents the researcher's interpretation of experience (the research process) shared and created by both researcher and participants. The place of reflection in nursing practice - a consciousness of self in interaction with others reflects into research practice within the profession as a move away from a dependence upon naive realism.

Van Maanen wrote in 1982, "Qualitative researchers are, in a sense, out of the closet. They are less apologetic, no longer publicly representing their practices as but crude precursors to...studies undertaken to verify and promote particular theoretical positions" (pp. 13-14). A glance at the literature since this time would suggest that Van Maanen's optimism was somewhat premature, as writers bemoan the subsidiary place granted to qualitative work both in academic and applied fields: Margaret Anzul (1991) suggests that qualitative research is written off as 'soft' or 'easy'; Morse (1994) supports this, pointing to the lack of explicit method as part of the reason ; Nagle and Mitchell (1991) reflect upon how slow the acceptance of qualitative research has been within nursing. However, the following discussion, acts as a rationale for the research approach. The issues of the 'how' and the 'why' underpin both the topic of the research and go some way to explaining the relationship between the knowing and the known. The 'reality' reported in the research (and, indeed, any 'reality') is created by the

actors within a situation. The researcher is one of these actors and thus the research world and data are created mutually by the researcher and participants. The final script - the known of the research - is an analysis and interpretation of that world, created through the researcher's understanding. The research process is seen as a dynamic evolution dependent upon the contribution of both the research participants and the researcher. In order to achieve this the researcher must be a reflective worker, conscious of his/her act of creation of both the research world and the final script. The movement towards an acknowledgement of the vitality of the research work is traced below.

Historical Issues

The history of qualitative research itself, and as we shall see in the later section, the method point strongly in the direction of reflection. Denzin and Lincoln (1994) suggest five moments in the evolution of qualitative research. The first of these, the traditional period reflected a positivistic paradigm, the researcher being seen as a professional, blank stranger who relayed 'facts'. This changed into a style which emphasised movement and richness - the Chicago School - but which faded into the second, Modernist, phase. The importance of rigour was re-established and writers were attempting to formalise the approach. "Thus did work in the modernist period seek to clothe itself in language and rhetoric of the positivist and post positivistic discourse" (p.6).

A reaction to this was seen in the next phase (1970 - 1986) of blurred genres which, as the name suggests, witnessed the breakdown of barriers between forms and an expansion of theories which were used by qualitative researchers. This blurring precipitated the emergence of two crises in the following phase. firstly, the crisis of representation which reflects the thought that

" experience is created in the text, not reflected in it" (Denzin and Lincoln, 1994, p 10); secondly, given the above, the question of how to evaluate qualitative research - the crisis of legitimation. The fifth moment - the present - is also concerned with the representation of the researcher and 'other'. Many of the issues raised here are of crucial importance to this research. For example, the issues of validity and reliability seem to be so much part of our cultural heritage that they have mutated over time, despite challenges from other tools of evaluation - such as the placing of the author in the work, from its inception, or conception, to completion. Whilst bearing these questions in mind, it might be useful to attempt a definition of qualitative research.

Through the literature these range from those which place the emphasis on the underlying philosophy of the methodology to those which concentrate on method per se as the defining feature. An example of the latter comes from Strauss and Corbin (1990): "a non - mathematical analytic procedure that results in findings derived from data gathered by a variety of means"(p.8). And an example of the former : "Qualitative research is an interdisciplinary, transdisciplinary, and some times counter-disciplinary field. It cross-cuts the humanities, the social and physical sciences ... (it) embraces within its multiple disciplinary history constant tensions and contradictions over the project itself." (Denzin and Lincoln, 1994, p. 3). These two definitions illustrate some of the difficulties of working in and with qualitative approaches - the matter is not simply one of choosing a tool or technique, it runs to the heart of the question of the nature of knowledge : "When stripped to their essentials, debates over methodology are debates over assumptions and purposes, over theory and perspective" (Taylor and Bogdan 1984, p.1).

PRINCIPLES

The Emic Stance

A more fruitful approach might be to draw out the essential features of the qualitative enterprise. As many accounts exist as do research theorists and I have attempted to identify the themes which run through these. Perhaps the most important, a departure from post-positivist approaches is the attempt to view the world from the point of view of the actors within it - the emic stance. As we have seen above, the place and contribution of the researcher in the creation of this world is debated but the focus here is on capturing experience (Strauss and Corbin, 1990). In this piece, the means by which the research question is to be answered makes this principle a necessary condition of the work. I needed to ask the question, 'What are the emotional issues involved in caring for people who self injure?' of the carers who do that work and to attempt to understand that world. The more difficult issue of the contribution of the researcher will be explored in a later section of this chapter. A second theme, which is a necessary sequetour of the first is the assertion that reality is constructed by, "particular actors at particular times, in particular places" (Schwandt, 1994 p.116). Whilst seeking explanatory frameworks which may be useful beyond the immediate research scenario, qualitative researchers recognise that individuals are active in shaping their worlds and that these do change. This work was undertaken acknowledging that any broader utility of the work would rest, not upon issues around samples, judgements about validity etc., but upon the quality of interpretation (Silverman, 1993). The theory which emerges from this work could be used in other situations which appear to present similar challenges to carers. Thus it is the conceptual work which follows from the data gathering and analysis which constitutes the wider utility of the work.

Revelation

"The aims of revelation and disclosure take precedence over explanation and prediction" (Van Maanen et al. 1982, p.16). The focus within qualitative research is on description as a means of explaining and knowing that which is described. This rich description will enable patterns of behaviour, of emotion, of interaction, to be drawn out which illustrates the next theme : induction. Within my research a very specific question was being asked, but the data provided a full and colourful picture of the context within which the question was answered. The principles which have already been discussed indicate an inductive process of theory - generation. Many ways of eliciting theory from data may be used : in this study a grounded theory approach was considered the most appropriate and is discussed below. This 'thick description' also allows for two other foci of qualitative research : the study of change/process (Denzin and Lincoln, 1994) and the acknowledgement of the difficult relationship between meaning and action (Strauss and Corbin, 1990).

Understanding these principles through reading and, more pertinently, through experience led to a huge change in the 'plan' and in my expectations of the work. At the beginning of the research I was rather naively hoping that the answer to the research question would be some kind of emotional-developmental trail, leading to wherever the individual participant perceived him/herself to be. However, it quickly became apparent that the research participants were not going to provide a neat and tidy story, relating a chronological tale of emotional change. Rather, I would have to understand that the mechanisms which enable these nurses to continue to care are dynamic forces within and around the relationships they form with the learning disabled people for whom they care.

Altheide and Johnson (1994) write, " The nature of meaning and its unfortunate location

between language and experience produces an imperfect fit "(p.492). The explanation rendered in the research comprises my interpretation of a mutually created research world. It would be useful, at this point to elaborate upon this process. Social constructionism views reality "as collectively created, shaped by the conventions of language and other social processes "(Schwandt, 1994). The research world is created through language by me and the research participants. This implies that, in knowing the world, one adopts a relativist ontology and naturalistic methods. Knowledge is unfolded through a continuing dialogue, working towards a description which fits the mutually perceived realities. The text then comprises the writer's interpretation of what s/he has learned related to broader contexts and theories. However, the leap between the participant's experience, the language used, my experience of this and my interpretation and expression of it all contribute to the tension of creating a theoretical framework which "fits" the research world (Schwandt, 1994). In order to recognise the complexity of this process, one must acknowledge the continuing dialogue between past and present (how we re-write our histories and how they shape our future) would be necessary to achieve this wonderfully tidy answer. Through the research it has become apparent that there is no 'trail', and that which we might view as the past is inevitably in the present. The theory generated from the research data frames the caring process not as a chronological tale, but as a continuing tension between opposing emotional forces. Qualitative methods allow room for this realisation.

The Creative Act

A theme which I feel is important is mentioned by some commentators - that qualitative research is a craft which involves skill and imagination on the part of the researcher. Taylor and

Bogdan (1984) contrast this with a 'recipe' which could be universally applicable and easily followed. "In a very real sense the artistry, the craft, the workmanship of qualitative research is to be found at the boundaries of any given study" (p.18). Undertaking a piece of research by interview and grounded theory involved both periods of fairly dull work - literature reviews, transcription - but also moments 'at the boundaries'. The interviews themselves involved skill and creativity; the analysis of the material called for imagination; the realisation of overall patterns and processes in the research findings required conceptual leaps.

The Role of the Researcher

This issue represents a critical difference in constructivist research from other qualitative approaches as the researcher's part in the creation of the data and his/her interpretation is acknowledged and explored as vital in the research process. This is obviously quite different from the 'reproduction' model, which casts the researcher as an objective reporter who merely reflects reality (Hammersley, 1992). Further, it differs from the confessional tale, in which, "the attitude conveyed is one of tacking back and forth between an insider's passionate perspective and an outsider's impassionate one... A delightful dance of words ensues as fieldworkers present themselves as both vessels and vehicles of knowledge" (Van Maanen, 1988 p. 77). The change to constructionist tales occurs through an increasing awareness of the consciousness of the researcher, which Van Maanen (1988) describes as "a dialectic between experience and interpretation" (p. 93). Abandoning the attempt merely to capture the participant's voice and reflecting upon one's own part in the construction of the research raises the danger of what Stacey (1988) calls 'the delusion of alliance'. She suggests that ultimately, the researcher will control and own the research with the participants having been used in a parallel although different way than in a positivist approach. Kleinman and Copp (1993) reflect this theme

commenting on the fact that researchers often report feeling guilty as the research progresses over how the participants might feel about how one is interpreting and presenting their experiences. This was, indeed, the case for my research. The reporting back to the research participants of the themes which had emerged from the first round and the refinements of these from the second, caused me some anxiety as I was concerned that the research participants would no longer recognise 'their' work in this work. However, of greater concern was the interpretation of the data. I felt that this theory touched upon very personal and private areas for the participants in relation to their work and was uncomfortable about exposing these. In fact, many of the participants were fascinated by the theory and wanted to spend time talking about it and using it. Silverman (1993) suggests the idea of any form of partnership within research is misguided, and that any interaction will be shaped and controlled by the researcher. I feel that Silverman is misreading the situation: participant and researcher together comprise and create the research world and at the stage of face to face interaction the researcher, within an unstructured interview, for instance, will be asking the participants to raise the agenda. The acts of analysis, interpretation and writing inevitably move the researcher away from dialogue with the participants. It is in writing, Schwandt (1994) suggests the author claims authority. The analysis and interpretation of the research through theoretical frameworks by the researcher necessitates both cognitive and emotional investment in the work.

Part of this process of moving away from the research participants is the making unfamiliar of the familiar. One must explore the tacit knowledge shared with the research participants which may include, "deep structures of emotional memory, collective unconscious" (Altheide and Johnson, 1994). This phase also brings the realisation that despite shared experiences, and, in the case of this research extensive common knowledge, one cannot assume access to others'

hearts and minds. The 'truth' for others is inevitably different from one's own : the task is to feel, understand and interpret those truths. However as Webb (1984) suggests, this does not allow the writer to abandon academic and methodological rigour and the final part of this section of the chapter deals with this issue.

Personal Investment

However, I felt it is also important to acknowledge that the investment which the research participants and the researcher make in their constructed world are different. Paralleling the move from an emotion - free nurse to an emotionally articulate practitioner, the emotional aspects of the research process are beginning to receive more attention within the literature (see Ely et al., 1991). "It is typical for the researcher to experience a slew of unanticipated, perhaps chaotic or disorganising emotions during the course of the research" (Friedman, p. 109). Certainly, the research has proved an emotional as well as cognitive adventure. The feelings that the researcher experiences over the course of the work are now recognised as an important part of the process. I think these emotions maybe seen at two levels. First, the emotions which are initiated by the 'content' of the work - as an example feeling sad for and with the research participants, in discussing past events which have distressed them. The second, I would suggest is more focused on the work as work - feeling elated when writing flows, feeling pressured by schedules and deadlines.

Friedman reports that many researchers experience anxiety and my anxiety had two foci : the minor worries (will I be able to access a particular article/book? will the tape recorder keep working?); and the major anxiety (can I actually do this?). These minor anxieties feature throughout the fieldnotes, the major only as 'finishing' became a possibility. Garner (1991) discussed another emotional reaction which is pertinent here, that of avoidance. She cites the

instances of researchers continuing to collect data as a means of avoiding the formal process of analysis, and she cites Van Maanen (1988) and Bogdan and Billen (1982) who share this experience. In my case clinging onto the known was a defence that I used throughout the piece. I was reluctant to leave the background literature review and start interviewing, reluctant to stop interviewing and start analysing, reluctant to return for second interviews etc. Kleinman and Copp (1993) focus on coding in this context, suggesting that the process of coding with its fine detail and repetition can give the illusion of competence. We may draw another parallel here - consideration of some of the approaches taken towards self injurious behaviour itself. Hanging onto the 'known' - even a known which may not be productive or effective - provides an emotional security which is lost in the move to a new approach or activity.

Another arena of interaction which influences the researcher's experience of fieldwork is the intrapsychic. Whilst most analysis of the process and data is at the social/cultural level, attention to unconscious processes will add a further dimension. Hunt (1989) suggests that we need to be aware of our own motivations and any distortions they may bring to the research. Certainly, I was tuned into my own emotional reactions to the research situation, and recorded some of these in my field notes. Within the interview situation, I did note feelings of irritation, impatience, and some elation and attempted to trace these.

Rigour

"What is an adequate warrant for a subjectively mediated account of intersubjective meaning?" (Schwandt, 1994 p. 130). The attempts to answer this question are many and diverse and so I shall attempt an account of these following Hammersley's (1992) schema. Essentially, Hammersley suggests three positions are presented in the literature.

The first of these is the rejection of evaluative criteria; the argument being that the philosophical underpinnings of qualitative research run counter to the concept of measuring the work against pre-determined criteria. The essence of the enterprise is that of sharing and growth and so it must be judged on those grounds (Hammersley, 1992). The difficulties inherent in adopting such an approach are clear. The endpoint is an extreme of solipsism and relativism.

A second approach has been to apply criteria from quantitative research to the work as witnessed in Denzin and Lincoln's (1994) account of the Traditional Period. " ...qualitative researchers should not rely on the use of quantitative criteria such as validity and reliability to explain or justify their findings. Such dependence reflects a lack of knowledge of the different purposes, goals and philosophical assumptions of the two paradigms" (Morse, 1994, p. 96). Indeed, the difference of aim and of intention preclude the use of these criteria in their quantitative form. These criteria of the validity and reliability of the research are, as they stand, inappropriate to the work undertaken and many authors including Hammersley have suggested a reformulation of the concepts to fit the approach. Hammersley himself suggests that we reframe validity as truth: "An account is valid or true if it represents accurately those features of the phenomena that it is intended to describe, explain or theorise" (Hammersley, 1992, p. 69). The question of judging the claims is one to which we shall return below but Hammersley suggests that the criterion here should be the adequacy of the supporting data. Other reformulations of these essentially positivistic criteria have been suggested. Altheide and Johnson (1994) report the attaching of validity to other concepts, e.g. validity-as culture, validity-as-gender, in order to shift the focus of the criterion.

The third approach to the evaluation of qualitative research is the utilisation of criteria specific to ethnography. Many combinations of these criteria exist. In the same way in which a definition of qualitative research proved difficult because of the differing emphases of authors, teasing out common themes in the criteria proves a difficult task. Some of these evaluative schema concentrate on the 'outcome'. Lofland and Lofland (1989) suggest we look for a generic framework which is novel, elaborated, eventful and interpenetrated with empirical materials. Other schema emphasise the process more with detail required of (for instance, in Altheide and Johnson (1994)) the contexts of the research, the participants, the schedules, division of labour rules etc.

However, it would appear that the utilisation of a set of principles of evaluation is probably the most balanced approach, and again these abound within the literature. Guba and Lincoln (1981, cited in Hammersley, 1992) suggest: credibility (judged by the participants); applicability, through transferability rather than generalisability; consistency; neutrality in the sense that analysis is grounded in data. Leininger (cited in Morse 1994) suggests : credibility which "refers to the 'truth' value or 'believability' of the findings that have been established by the researcher through prolonged observation, engagements or participation with informants or the situation in which cumulative knowing is 'believable' " (p. 105) ; confirmability via, for instance, audit trails; meaning in context; recurrent patterning; saturation; transferability. Schwandt (1994) uses : fit (the closeness of theory and data); the extent to which the research works; relevance; flexibility. To return to Hammersley (1992) he suggests truth, as above, and relevance. Truth may be assessed through ; plausibility and credibility gained through evidence from the data; centrality of the claim, and consideration of the type of claim made - whether as definition, description, explanation, or theory. The relevance of the work may be assessed via

its importance to the field and its contribution to the literature. Altheide and Johnson (1994) also use importance as a criterion and add relevance, credibility and plausibility. These are then coupled with the more detailed list reviewed earlier, and another checklist to cover an account of what the researcher actually did.

The generation of a definitive checklist would appear contrary to the spirit and heart of the qualitative undertaking and would be constricting for both researcher and reader. However, I am suggesting that the principles outlined above may be used where appropriate and in appropriate combinations. Each reader will construct the text as s/he perceives it and this will inevitably lead to the generation of his/her own criteria for evaluation. However, given the epistemological stance taken, some guides to evaluation present themselves. The first of these is credibility - the research findings must be believable in terms of the data from which they were generated - and also in terms of the explicit means by which they were reached. This chapter has presented the means by which the move from interview to theory was made. Another means of assuring this is through checking with the research participants. Consultation with the research participants was undertaken in this study but, as Garner (1991) points out, this does present some difficulties, not least that the research participants may not fully understand the research process. The second principle I feel to be crucial to meaningful evaluation is that of dependability, a coherence and congruence throughout the entire research project. This would reflect in the congruence of philosophy, methodology and interpretation, and would imply integrity on the part of the researcher. This may be what some commentators call consistency. The way in which this work is presented - with the discussion of rationale, context, method, methodology findings and interpretation - is a demonstration of this consistency. Lastly, the concept of transferability is important. "Because the goal of qualitative research is not to

produce generalisations, but rather in-depth understandings and knowledge of particular phenomena, the transferability criterion focuses on general similarities of findings under similar conditions, contexts, or circumstances"(Leininger, cited in Morse, 1994, pp. 106-107). Hammersley (1992) raises the question of the universality of findings given the data analysis methods within qualitative research. However, as many authors (including Hammersley) have pointed out, the question of, 'how good is this' must be preceded by the question 'what is this for?' Within a practice profession - nursing, for instance - researchers have a responsibility to ensure that research results are utilised and the aim of undertaking this work is, ultimately, better care and caring environments. Thus, what this piece of research is 'for' is to enable services to support better those who care for self injurious learning disabled people. Any innovations which spring from the research must themselves be evaluated and, it is hoped, the criterion of transferability demonstrated.

However, these guiding principles for evaluating qualitative research are not presented for use as a post hoc tool. Evidence for evaluation should be taken from the project as a dynamic process : the account of the research, the final script and the research interpretation should, holistically, answer questions of evaluation.

This chapter has presented and discussed the process which I undertook in order to answer some questions around caring for people who engage in self injurious behaviour. The following chapter reports the analysed data , describing and discussing the emotional components of the research participants' work.

CHAPTER FIVE

THE RESEARCH FINDINGS

IS THIS WHAT YOU MEAN?

CHAPTER FIVE :

RESEARCH FINDINGS : IS THIS WHAT YOU MEAN?

This chapter presents the data which emerged at the end of the analysis process described in the last chapter. The material is presented in a simple fashion - each theme is introduced, described and illustrated by the research participants' words. This simplicity of presentation is intended to achieve two aims. First, that of laying out the materials from which the explanatory framework (the data interpretation, presented in the next chapter) is woven. Thus the reader is enabled to follow the process through, as the material on evaluation in chapter four suggests. The second purpose is to continue the illustration of the misfit between the models outlined in chapter three, which purport to describe and define the concept of care and the situation in which the research participants find themselves. As the material in this chapter will demonstrate, I suggest that huge differences exist between care in the realm of acute physical illness and care within 'long stay' situations. The defence mechanisms needed and used by carers differ accordingly. In the short term care situation, carers may use and re-use the same defences - and, perhaps, become practised at them. The material presented in this chapter suggests defences in the longer term setting constitute a continuing, dynamic process, with no 'end point' but an evolution over time.

As the previous chapter related, the codes and categories generated in the research were sent to the research participants for validation - asking the question, 'Is this what you mean?' One of the difficulties with this approach is that the condensation of many conversations into themes necessarily led to the loss of the finer nuances of communication and this was noted by a few of the research participants. More commonly, having the themes presented so starkly led to some consternation on the part of some of the interviewees who took the opportunity of the second round of interviews to explain/expand upon their earlier conversation. The case of the

young man who denied crying, having previously suggested this, is an extreme example. However, the participants generally appeared to think that the themes presented below represented their feelings competently.

Whilst, as reported in chapter four, the second round of interviews were shorter than the first, the accumulation of these two seem to be more meaningful to some of the participants than was the eventual theory generated from them. Many of the participants still talk to me about the themes and how they still use/ see them. The theory has provoked interest among the qualified staff and the service managers, who are using it as a basis for staff support.

The themes presented below emerged from the mass of data via the analysis process described in the previous chapter. The findings from the research appear here in three parts : first, the participants' reported emotional reactions ; secondly, the behavioural concomitants of these; and thirdly the belief systems which appear to underpin these feelings. This appeared to be the simplest way of grouping the emerging themes and to be a logical presentation in relation to the work undertaken by the research participants. More complex means of grouping the data, as discussed in the previous chapter, were rejected, and the participants' reaction to the schema would seem to validate this approach.

One of the aspects of the data analysis which surprised me was the lack of difference along axes I had expected to divide the research participants. The first of these was gender : I had supposed (in a rather gender-stereotyped way) that the women included in the research would be more able to disclose and discuss their emotions. Generally (with the notable exception of one monosyllabic male nurse) this proved not to be the case, with one exception which is noted in this chapter. In analysing the data no profound differences of either experience or expression

were found and the shape of the interviews (how much I said/ how much they said) demonstrates no significant differences. The second axis was that of the expected difference between care assistants and qualified nurses. Throughout this report of the data analysis I have indicated where differences along this axis were apparent, but generally the responses were not marked by difference in these two groups.

It is worthy of note at this stage that throughout both rounds of interviews research participants expressed a great deal of hesitancy in their conversation. This is indicated in text extracts below by the use of continuation dots ("....."), and these represent hesitation rather than edited text. All quotations used are complete : additional edited material is presented in parentheses. Early in the research I attributed these hesitancies to asking people to talk about a subject which may have been unfamiliar or uncomfortable for them but as the work progressed it became clear that ambivalence - expressed in part through this hesitancy - played a large part in both the content and manner of the participants' thoughts and reactions and their emotions.

Much of the material presented in the interviews was relayed in the form of stories, and this reflects a more general recognition in nursing research and theory that the 'tale' is an important genre for the relating and reformulating of nursing knowledge (see Parker, 1990). If nursing/caring is embodied within the nurse-patient relationship, this can be revealed via the 'telling' of this relationship. Thus, for many of the research participants, the first round of interviews followed the story, or several stories of how they came to be in this job, and how they continue to do it. The second round of interviews tended to be more analytic, but all of the interviews were peppered with stories of interactions with clients, illustrative of the point/s being made. In focusing on one aspect of these tales, as is necessary for this piece of research,

much rich and informative material is excluded. I have attempted to present the findings in a way which reflects their telling.

EMOTIONS

SHOCK

In their descriptions of initial reactions to self injurious behaviour, the term 'shock' and 'shocking' were used frequently. This first reaction was often described in great detail, along with the incident which occasioned the response. A link between shock and an inability to see the cause or reason for the behaviour is clear and this reaction is enlarged upon, often in the form of a narrative :

"I was horrified...especially with P., because he used to crash hell out of his head... it was just awful, you know..."

"I was appalled, quite honestly, and I didn't know what on earth to do..."

On reflection, during the second round of interviews the fading of this reaction was noted with, on the one hand, some regret and on the other, with some relief.

"Oh, no, it's not like that now... I mean, I hope that isn't that I've got hard to it..."

"I don't know, Maggie... is it sort of getting used to it.... but I'm not shocked by it now..."

And then :

"I really felt for (them) then.... but that's gone... even with someone
new it doesn't get to me anymore... just as well really.. I mean,
I couldn't go on like that..."

This regret was, I think an acknowledgement of the humanity inherent in the shock reaction and of its loss. However, the research participants appeared to be saying that such emotional reactions could not be sustained and their blunting led to an ability to carry on working with this client group. Fear of becoming blunt, or hardened to the behaviour is reflected in a theme below (see 'Belief Systems').

PANIC

This category was reported by many of the participants although the reporting of the emotion varied from the use of the word, 'panic' (in one case repeatedly) through to describing a combination of feelings and behaviours which I have interpreted as within the range of this category : e.g. the feeling of having to intervene in the behaviour with great urgency, accompanied by an overwhelming sense of fear and/or dread. This feeling and the behaviour which accompanies it appears to create conflicting reactions in the research participants. Their panic seemed to be a natural response to them, at the time, but was seen as inappropriate for those in the role of carer.

"I was no use when people used to self injure.... at the start...
I'd just be getting so upset and everything, I just had to
stop them..."

"It just makes you want to rush in, but that's no good to them

really, is it..."

In the longer term, two things appear to happen. For some carers, the sense of panic subsides, and the urgency is removed from the situation. Sometimes, in this case, the behaviour is viewed clinically:

"Well, you know what you have to do... it's all in the care plan
you just do what it says there..."

For others, the repeated hitting of the panic button leads to a more cynical approach.

"I just think, 'Well, go on, you're going to do this, whatever I
do... even if I turn myself inside out... '... but then afterwards
I feel really bad about it...."

Although for some nurses the feeling of panic subsided with experience, for others, the feeling remained, but they modified their behaviour.

"And also... ummm... I could see a little bit of him creating
some panic in me... all of a sudden, he starts hitting
himself and that creates a panic and you've got to
join in."

INTERVIEWER: Is it (the panic) still there?

Yes, but I'm forcing myself to approach it in a calm way..."

Interestingly, the nurses for whom there was a 'modified' panic reaction, tended to be those professional nurses who had chosen to specialise in this field.

GUILT

One emotion which appeared to run through many of the others, as well as to stand alone, was

guilt. This is a complex emotion, even in its simplest presentation, but altered here according to the emotion/s it was mixed with, and also over time. One nurse discussed consistently feeling guilty when self injurious people engaged in this behaviour when in her care and discussed the way she always felt that she could have 'done something'.

Causality / Responsibility

The first type of guilt nurses felt was that occasioned by feeling that they had caused the self injurious behaviour. This feeling was reported particularly during the first few months of working with self injurious people.

"I thought... felt so guilty as if I had done something badly wrong ... and that it was my ignorance that had set this pattern of behaviour off and I was appalled..."

"I always feel regretful.... I'm examining myself.... have I spoken too sharply, was there a wrong tone.... I always feel a slight remorse. If only I had thought of something else, perhaps it might have been averted...."

"...but she just wasn't happy, and you think, 'My God, is it me?'"

Two obvious concepts at play here are causality and responsibility. At first, carers feel that they had caused and were, therefore, responsible for the behaviour. Later, however, although carers realised that they were not directly responsible for the self injurious behaviour they continued to examine and be critical of their part in its evolution and occurrence.

Institutional

A combination of personal and institutional guilt was reflected in the second category here. Some nurses identified the care system within which clients live as a causative/sustaining factor in self injurious behaviour. This was particularly the case for nurses who could reflect back over some years to patterns of care which were of a largely custodial nature. Many of the stories nurses told me dated from the 1970s and 80s and reflected the inhumane way in which people were expected to live and the inhumane job which carers were expected to perform. Ambivalence marked many of these tales with nurses reflecting, on the one hand, affection for, and sadness at the loss of those times : the perceived simplicity, solidarity , comradeship and fun. On the other hand, they also recognised and regretted the part played by the care patterns and the behaviour these required of the staff and client group in the destruction and denial of life chances and opportunities for people with learning disabilities and in the generation and maintenance of behaviours now perceived as 'challenging'.

" It was like... you knew everyone, and we all shared the same.. things.. you knew all the staff and all the clients..
Yes, Christmases were great..."

"It was a different job then, Maggie, it was really different.
You just went to work, got people up, did breakfast
and all that... there wasn't so much... problems.. like
now..."

For those staff who have been in the care system for some time, and for newer staff, even more recent care patterns raised mixed feelings. They reflected an awareness of the difficulties

inherent in the care system, whilst trying to distance themselves and the care they give from it. Ambivalence in the way these nurses view their current role was evident : aware of the sustaining influence of institutional care on self injurious behaviour, the care they offer on a one-to-one basis exonerates them from blame . However, guilt at still being 'part of the system' remains.

"Yes, you can improve people's standard of life, and can improve their daily living.. but you have to realise that we made.. well, not we personally.. but the system we work in made them like that.. I feel guilty about that because maybe I was part of it..."

"That's something awful I used to go home and think about.. you know I'm just going to hit myself really, really hard because I can't get any attention any other way'...."

This pattern of guilt has, I would suggest, become more common and stronger through the 1990s, a trend exacerbated by the growing number of auto/ biographies of people with learning disabilities which relate the appalling life conditions within institutions. We must beware falling into the trap of the condescension of history - the majority of carers were not 'bad' people, and the current trend to deny our professional past is, I feel, very dangerous.

Some of the nurses reflected much uncertainty about their guilt, sensing that, at some level, it was irrational, and yet feeling it pervade their interactions with clients.

"I always feel bad when they have a go.. even if we've been up town and had a nice day and then she starts, it wipes out the... fun bits..."

This ambivalence about their emotions reflected strongly in the next category of emotional reaction : that of irritation.

IRRITATION

The carers interviewed were very ready to discuss their irritation with me and between themselves, which initially surprised me. Nurses at all levels and from all backgrounds expressed a variety of emotions which I have categorised as irritation which cover wide emotional ground. Many talked about feeling 'wound up' or 'worked up' by the self injurious behaviour engaged in by individuals. Although this was often viewed as an unintentional side effect of the behaviour, it was occasionally seen as intended and, in both cases, had a heavy impact on the nurse's sense of well-being and his/ her ability to perform effectively.

"I just can't take to A... he really does wind me up.. he really annoys me ... uses... what is it? .. emotional blackmail a lot and I can't bear it..."

"It's sort of... like...umm... a feeling inside.. like a volcano inside you... it's churning you up ... it keeps winding you up..."

The carers reported perceived link between tiredness and irritation. Partly, this was seen as a result of working with people who can challenge : but again, ambivalence is evident here, as all of the carers participating in the work had chosen to work with this client group and yet rather resented the strain this put upon them.

"People who are need lifting and feeding and that... it's

much easier, because you don't have...

the noise and everything..."

Also, the organisation of staff rotas was blamed repeatedly for this tiredness. Interestingly, one of the homes in which the staff worked changed their work patterns during the second round of interviews, so that staff worked three twelve hour days instead of five seven and a half hour days. At first, staff expressed more personal satisfaction with this pattern, as the numbers of 'incidents' with the clients fell, owing, it was supposed, to better continuity of care. However, many of the staff reported that they did become very tired with this working pattern - a problem which was not solved either by working ones 'on' days together ("too long a stretch") or by splitting them up ("don't get time to recover properly"). The registered nurses who carried responsibility for the welfare of the clients also reported being unable to 'let go' and most of them reflected on the difficulty of leaving work at work.

"I sit and unwind when I get home... after being here with all the noise... but, of course, if you're on a sleep in.. you don't go home.. it's about twenty four hours with them when you sleep in and it's too much..."

"It's worst when you get a morning and then an afternoon then a morning. You know, you're there late, then back early in the morning, so there's no break..."

"....it's great for her... she gets care from me all day... but I get really, really, tired..... I wonder if she gets fed up with me, though?"

Many of the participants reported feeling emotionally drained by working with self injurious people. One of the nursing staff said that he felt 'used up' by being with demanding people, and that constantly giving, but not receiving 'care' or regard was an unreasonable demand on carers. The expectation of some reciprocity in the carer/ client relationship was evidently denied in some of the relationship that carers had with self injurious people. The efforts which carers put into 'looking after' individuals appeared to be negated by the behaviour :

"It doesn't matter what you do or who you are...

if she's going to go that day, she just goes..."

Further, framing self injury as a reflection of one's caring efforts throws into a dubious light ones reason for working.

Some of the staff identified the self injurious behaviour as intentional, the aim being to gain attention from carers or to achieve some other, desired end. Most of the research participants felt annoyed at being caught in a situation in which they could see no positive choice of action. To ignore the behaviour meant risking harm to the client - emotional and /or physical, but to respond to it was seen as reinforcing the self injurious behaviour.

"Then M. starts, banging her head and because she thinks,

'E. will come and sit next to me, then' and I think, 'Come

off it.. you'll have to wait while this person has a bit of

attention'. That annoys me, then..."

"Some of it is, I think, 'Look at me' and it is an effective

way to make you look at me if I bang my head on the

wall..."

The reactions to this perceived manipulation varied between staff and, in one individual, over time. Nurses reported a variety of emotions from feeling angry with the perceived manipulator, through to "desperately sad", for him/her. The range of feelings was reported frequently within one individual, revealing an ambivalence and uncertainty about emotional reaction. I noticed that much reassurance was sought from me during these instances, with the research participants using phrases like, "don't you think?", "isn't it?" and "you know?"

Reactions to those thought to be 'attention seeking' were different from those whose behaviour was thought to be differently intended. This difference is encapsulated by one nurse, talking about caring for a profoundly disabled person who is self injurious and not perceived as manipulative:

"I go home exhausted, but I don't feel so.... mentally..

twisted..., you know?"

This issue of the perceived intention of the behaviour and the effect that this has upon the carer's emotional reaction will be returned to later in this chapter. It was interesting here that there appeared to be a difference between the way in which registered nurses and care assistants viewed this behaviour. Whilst the care assistants viewed it as irritating and annoying the registered nurses took a wider view, framing it as damaging to individual carers and to the care team.

ANGER

Chapter three reflected the move within nursing to the perceived need for emotional articulate practitioners. However, strong negative emotions toward patient/ clients are still not acceptable within nursing even where the authenticity of the nurse / client relationship is seen as

central to the care process. Anger was expressed by many of the carers. In some cases, anger was directed at the client, as a response to frustrated attempts by the carer to intervene in particular episodes of self injury. Again, carers reported feeling angry and then feeling guilty at having felt angry. Thus, in interacting with the self injurious person and reacting with anger, all kinds of doubts about their own competence and worth assailed the carers.

"It still upsets me... I suppose it makes me angry in a way...."

"It just makes me so.... angry sometimes.. when he just has to do it and I get...hooked into it... it makes me so mad. And then I feel bad about that too, I mean that's (caring) what I'm here for, isn't it? You just can't win, Maggie..."

"... and some days I just can't hack it... I really feel as though M's getting on my case..... But I don't know.. I suppose he can't help it and I should be more... better with him.."

A few of the participants felt angry with themselves, in one case for being unable to prevent the self injurious behaviour:

"And then I get mad because I didn't see it coming.. or if I did and I couldn't think... how to.. stop it..."

Or alternatively, the anger is aimed at one's frustration and annoyance with the client:

"...it's not their fault, is it, and I get angry with myself because I get so ratty with them... when they won't stop, I get mad and then I get mad with me..."

Generally, higher levels of regret and self recrimination were reported by the registered nurses who felt (somehow) that their role and education should enable them either not to get angry and irritated, or at least not to show it. When pushed further on issues around honesty in the caring relationship some embarrassment was shown by the research participants. This, I think, illustrated the mixture of models referred to in chapter two. Whilst entering into relationships with clients which were premised on partnership and authenticity the carers still felt that they should, somehow, not show their anger - a remnant of the 'emotionally detached nurse'.

FRUSTRATION

Frustration was one of the most widely experienced emotions in the care situation. The participants used the word repeatedly and with much feeling. It was also linked, quite clearly, in the minds of the participants to a number of other emotions reported. Frustration with the self injurious individual was frequently expressed as a response to attempts to mediate/care for the person. This was mixed with anger or irritation as individual carers felt that their efforts to help were 'wasted'. This frustration was also linked for many, with feelings of helplessness in the face of the continuing behaviour. This helplessness is, I think, linked to the ambivalence carers feel about their work with this client group : they express enjoyment of the work, and yet many of the emotions expressed were negative. This perceived helplessness will be one of the foci for the final chapter of the work.

"I feel frustrated that all I can do is hold his hand..."

"I feel very, very frustrated... I am frustrated by this
behaviour... because it makes me feel.. inadequate..
very inadequate..."

Carers also felt frustrated with themselves, partly around their inability to affect that disabled individual and their behaviour, but also around their own reactions of anger and irritation.

"I'm not frustrated with them... I'm frustrated with myself
because I don't know how to..... this is a good conversation,
it's making me think for once.. I get frustrated with myself..."

In conversation, carers were able to discuss this frustration openly, and to acknowledge feeling anxious about this mixture of emotions. Nurses would turn to each other for support with these emotions, but were very critical of themselves. They were, however, not critical of each other over their emotional reactions and were generally very supportive. The only criticism of other nurses which occurred in the interviews was one carer being critical of others who failed to 'hand over' incidents of self injury.

FEAR

The concept of fear was one which cropped up repeatedly in the interviews, although in the transcribed data it became clear that the word was used to describe reactions to a wide range of situations, all of which in some way frightened the interviewee. Given the situation studied, the most obvious interpretation is that the participants were afraid that they would be attacked or injured by the person displaying the self injurious behaviour. Indeed, many of the carers did report this as one of their early reactions to the behaviour.

"It's human nature to want to withdraw... to draw back..
as I said, because you feel you may be the next target.."

"I found that (self injurious behaviour) very frightening
... and very disturbing... because I didn't know whether

he could be outwardly aggressive."

Many people who engage in self injurious behaviour, have multiple challenging behaviours and therefore the fear that the self injurious person may attack others is not unreasonable. At a different level, fear of being hurt oneself may be a recognition of the self injurious impulse in all of us. Thus, a rejection of the behaviour and a fear of it may not be merely concerned with attack from the other, but also with attack from the self. However, many of those who reported being afraid of being attacked said that this faded with experience, either of individual clients or with the client group as a whole.

"And I've found over time that it's a substitute for an
attack on persons rather than a preliminary to it..."

Some research would be interesting in this field to discover the relative incidence of self injury accompanying attacking behaviour or as a substitute for it.

Fear also seemed to be compounded by a perceived lack of knowledge : firstly, concerning self injury itself; and secondly of individual clients and their idiosyncrasies. In the first case, all of the carers interviewed expressed a lack of knowledge : this included staff who had very little or no formal 'care' education in the field, through to one nurse who had extensive post registration education in caring for people with challenging behaviours. For the former group, more education would, it was felt, lead to a greater understanding of the behaviour.

"It was never mentioned in school... I just don't feel
equipped to..deal with it..."

"If I knew why he did it.. it would be.. more understandable,
and I'd cope better..."

For the latter group, who had some education in the field of challenging behaviours, their feelings were around not keeping up to date.

"Well, I did the E.N.B. course in my last job, but I don't
have time to get to the library, now..."

"There are new things all the time, Maggie, and I can't... I
mean, I don't really read or anything...."

This may, indeed, reflect the nurses' attitudes to their 'hands on' work or may be an echo of the current requirement within nursing for continuous professional development filtering into their everyday work. Again, for those carers who did read, little of the material was perceived as useful. The type of literature reviewed in chapter two was seen as too remote from daily work, and any literature which was not disability - oriented was seen as irrelevant.

When related to an individual client, the fear was that staff might say or do 'the wrong thing' which would trigger an episode of self injurious behaviour and, once it was started, the carer would not know how to stop it.

"I felt scared of saying the wrong thing to him... maybe
he felt that because I always thought he had a go
when I was around....."

As the literature review in chapter two illustrated, the establishment of a caring relationship is seen by many theorists as central to nursing and for all of the participants in this research, the relationship with the client was crucial. From it, they derived their job satisfaction, and sense of achievement. All of the research participants spoke about the enjoyment and satisfaction they gained from their jobs and of finding their relationships with some of the people they cared for

rewarding. Nurses prefaced their interviews by expressing the feeling that it was being able to offer care and to receive acknowledgement and affection (comments on p. 160 notwithstanding) which outweighed the more emotionally demanding aspects of the job. Also the research revealed that an atmosphere within which kudos is gained from the closeness of relationship ones clients seemed to be emerging, with one's worth as a carer being based upon the level of intimacy achieved. On first meeting a person with self injurious behaviour, the staff appeared afraid of the individual and the behaviour, but on closer acquaintance, the fear faded. Thus, being moved to care for different people, or having new clients move to a residential unit, caused concern among carers.

Another type of fear expressed was that of the damage that individuals would do to themselves when engaging in self injurious behaviour. One factor which came into play here was rather a convoluted sense of shame : the outward signs of self injury (bruises, scars, raw areas of flesh) were viewed by carers as embarrassing for the learning disabled person and for themselves. One carer said:

"People stare, don't they, when she's got plasters
and that all over her hands and up her arms..."

This carer didn't appear to think that this learning disabled woman's unusual appearance, gait or noises would attract attention, but was morbidly aware of the stigmata she bore. The registered nurses saw this as an extension of the discrimination from which learning disabled people suffer : that 'the public' do not understand (disability / self injury) and are therefore likely to be curious or just plain hostile. Among the unqualified carers a few expressed the fear that other people might think the wounds had been inflicted by them or that these signs of violence might be interpreted as a signal that the individual who bore them would be violent to others.

Concern about individuals worsening their physical brain damage emerged during the second round of interviews, when this issue was pursued. Some nurses expressed the fear that head-banging would lead to further disability :

"Stands to reason... your brain's not meant to be...
bashed around.... look at all those boxers... they've
got brains like mashed potato because of it..."

Some time during the second round of interviews was spent in trying to trace the cause of this embarrassment, but the research participants had difficulty in articulating why some aspects of self injury caused them such discomfort. For some of the carers, a process of cutting themselves off from the damage was acknowledged, and this caused some embarrassment. The example given, although extreme, does represent the distancing evident in many expressions:

"It does frighten me that one day he'll have a heart attack, and
probably will one day.... but that's only selfish on my part,
because I don't want him to have a heart attack if I'm on his
group..."

Staff also expressed the belief that the experience of pain in these individuals must be different from their own pain perception. However, further conversation with these same staff also revealed contradictory views :

"Well, I don't think P. feels pain in the same way... he
can't, can he, or he wouldn't do it.... would he?"

And later:

"My God, the way P. crashes his head... he must be

desperate to hurt himself like that...."

Another major way in which the ambivalence within the care situation was reflected was in the sense of failure expressed by the research participants.

FAILING

A feeling of appearing to fail in the care of this client group also featured in the participants' conversation. Although the data reflects the interviewees' ability to stand back from the situation, participants said that they felt they had failed the client and themselves if self injurious episodes took place during their span of duty. For many of the nurses involved this was linked to their sense of responsibility for the clients in their care and they were afraid that any self injurious behaviour by an individual in their care reflected upon their own ability. Consequently, they feared the self injurious behaviour starting.

"It's sort of a failure where you haven't had a shift where

A. hasn't had a go... it's nice to hand over that he's
been good..."

Associated with this category is the whole issue of the aim/s of care for this client group and during the second round of interviews, more attention was paid to this sense of having failed. Whilst carers felt that a person's self injury was largely beyond their control, the sense of responsibility and the need to 'do' something persisted. On further discussion, it appeared that carers felt the occurrence or not of self injurious behaviour reflected upon the relationship they had with the individual and also upon the environment they created through their interactions. As we have seen in the literature review on care the issue of the centrality of the carer/client relationship to nursing and to 'care' has enormous implications in this context as recording or

'handing over' incidents of self injury was viewed as an admission of failure.

The care delivery system within which nurses work may have added to this sense of failure. The adoption of a problem-solving approach with self injury being framed as a problem to be solved by the nurse may lead to an expectation that the behaviour can be 'treated' and will disappear. Indeed, many of the staff were involved in prescribing/carrying out care programmes with this ultimate aim and explaining these interventions constituted part of the discussion which I had with some of the carers. However, the intractability of the behaviour militates against this and may add to the sense of failure.

COPING

One word which appears frequently in the transcribed data is the word 'coping'. Nurses use this to refer to their own interaction with self injurious people and to their own defensive/supportive strategies. As an example of the former :

"I feel incompetent, really, that I can't think
of something else the person would like to do.... other
than self injure... I'm just not coping with it.."

"If you look at it over time, then they're (incidents of self-
injury) not that bad... but on a day-to-day basis, I feel that
.... as the team leader... I'm just not coping..."

Staff often reflected on their own inability to 'handle' the emotional consequences of witnessing this behaviour, viewing this as a shortcoming :

"...but you do try.. but then you think, 'You're no good

at it, C... you're really not coping with this..."

"I didn't think I was going to last my probation, the
three months. I thought, 'This is it.. I can't handle
this..'"

One situation which was mentioned by staff was that of asking another nurse to 'take over' the care of a particular person for a short period during a span of duty. This was very much seen as not being able to cope, and was avoided by some carers whenever possible. Interestingly, even in groups which perceived themselves as mutually supportive, this request for assistance was still self-evaluated negatively :

"Sometimes, you just have to say to someone else, 'Can
you deal with this? And that takes a lot of courage to do..
because it's the thought you can't cope..."

"It's not nice to think you can't cope with a situation
but you have to.. for your own self preservation, let
alone theirs...."

How 'coping' was interpreted varied between individuals: some saw it in terms of adhering to the care plan ; others in terms of maintaining their and the client's emotional balance; others as merely 'keeping order'. This was an issue which appeared to trouble the registered nurses more than the unqualified carers as they felt that they were ultimately responsible : "the buck stops with me".

Longer term coping was something which concerned many of the carers : none of them

envisaged doing this work for many years. Although they had positively opted for working with people who are challenging, the levels of energy and enthusiasm needed to continue with it were viewed as prohibitive to longer term involvement. For unqualified carers the end of this work was seen as being in a move to a different client group, or even a different job. One interviewee, who had been in care work for eight years said:

"I had spell with the elderly... it was... a rest,
really, but I've come back to this, now..."

Another, talking about work patterns in residential care:

"I don't want to be getting up at that sort of time
when I'm forty!"

Again, ambivalence is evident here. The professional nurses had a commitment to the particular client group, undertaking much of their work in their own time, and engaging in continuing education courses around the needs of the client group. However, most of them also saw their futures away from the direct care situation, with careers which would take them into management, consultancy or education.

GETTING USED TO IT

The initial impact of self injurious behaviour on individual carers was quite clearly remembered in all cases. Even for those who had worked in the field for some years, these early experiences were easily recalled, reflecting the impression made. Most of the interviewees also revealed that the impact of the behaviour had changed and diminished over time. This concept of 'getting used to it' was one which was mentioned quite early on by some staff in the interview process, but actually closer examination revealed very complex thought and feeling patterns, rather than

a linear reduction in the initial emotions.

"I suppose I was already used to that behaviour and
I just accepted it..."

"Nothing's new... I don't like them doing it, but if you've
put up with them doing it for five years, you get used to
it..."

That individual people with learning disabilities engaged in self injurious behaviour was something that carers got used to as part of the process of getting to know the person, and indeed, actually saw the behaviour as part of the person. Some staff reflected that their reaction to all self injurious behaviour was more muted than it had been at first but for some, their early contacts with 'new' individuals with self injurious behaviour continued to be just as shocking :

"I'd obviously seen it before, but when M. did it for
the first time, it was really frightening..."

"It's when you see someone you don't know doing it
(head banging) that you see.... realise...again."

During the second round of interviews, on being questioned more closely, the research participants reflected some uncertainty about whether this 'getting used to' self injurious behaviour was something which happened as a matter of course, or something they did, as a form of defence. The inability to sustain the level of horror felt during the first contacts was also discussed.

"It would just ... burn you... if you felt like that
every single time..."

"Sometimes when I come back from a holiday or something, I forget... I don't... psyche myself up for it, and then it's (the horror) all there again."

However, for some, this process of fading was gradual and almost unnoticed. One carer, who had come into the work after 'retiring' from another job said:

"I don't know, either they changed or I did.. but it just wasn't so bad after a while..."

For staff who expressed a belief that they had 'hardened' to the behaviour, this formed a cause of concern for most of them, as they felt it lessened their ability to care for the self injurious person effectively.

"Yes, I do try to think, 'Am I getting hardened to it?' and I do think we should have strangers in who give their point of view..."

"It's the wrong thing to get used to, and all because you forget there's a reason behind it..."

The awareness of the dangers of hardening to the behaviour actually made some staff very careful of their own responses and care practices. A checking and re-checking of their emotional responses was part of this process, and one nurse commented:

"Talking to you like this is like getting those those thoughts that go round your head... out and you know, having a good look at them..."

ACCEPTANCE

Even in the first round of interviews, a few staff talked about 'building up a barrier' between the self and the self injurious client, and of their awareness of this change in themselves. This was reflected partly through the issue of 'fatalism' (see below) and also through 'getting used to it' (see above). The concept of accepting the behaviour was also pertinent here. Two separate types of acceptance feature. The first of these was the acceptance of the behaviour per se: that it is a behaviour in which some people engage.

"But... I don't know... not until a good three or four months did I begin to accept it. Accept it as... part of the job... part of life..."

"But the bad thing is that you do become more accepting of it... which isn't particularly good, really..."

On re-reading the transcripts, it appeared to be carers who had more experience of dealing with the client group who talk about the behaviour separately from the people who engage in it and who thus expressed this kind of acceptance. For these staff, self injury was viewed as a fact of life and although unpleasant, needed to be assimilated as part of one's work. The other category here reflected acceptance of the behaviour as part of individuals and part of the relationship between the carer and client. The thread is picked up again below, in the section headed 'fatalism', but for many carers was a function of 'getting to know' the learning disabled individual.

"Well, that's P. really, isn't it? Love him, love his ear-bashing!"

"J. has always done that, Maggie... it's her, isn't it..

it's how... she is..."

EMPATHY?

Empathy as a concept has received much attention in the nursing literature over the last few years, and, as a skill is viewed as central to care. This literature was reviewed in chapter two, but it is interesting that it was raised early on in the research by the participants. Several of the nurses in the first round of interviews explained that they tried to see the behaviour from the client's point of view. Attempts were made by these carers to gain some insight into how the situation of individuals who engage in self injury might lead to the behaviour. At this stage none of the problems associated with the concept were pursued.

3. "I've thought, 'How does F. think?' Because he's blind and deaf, I don't know how much he knows.. so I started to think about how he thinks and I've looked at him just after he's hit his head...."

In deeper discussion, it appeared that some nurses were expressing an intellectual understanding of what circumstances might lead to self injurious behaviour rather than an emotional understanding of it. For the carers in this group, there was also a rejection of the understanding of self injury at an emotional level:

"But what are you going to replace it with? That'll give him the same sense of satisfaction we have when we have a good cry or talk to someone about it?"

And from the same nurse :

" But you can't imagine feeling so.... well... so's
you'd want to you know..."

In the second round of interviews, these issues were followed up more closely and did raise some difficulties for the research participants and for the research process. Asking the carers to be more explicit and detailed on this issue led many of them to face some contradictory concepts they held about the behaviour. In turn, this led to hiatuses within the interview process with a huge increase in the number of questions asked of me and, in one case, a carer becoming very defensive. When pressed, these nurses said they could understand the behaviour in the learning disabled person, but not in themselves, although there was a huge degree of ambivalence over this.

"I don't think I'd ever do that (skin picking)..
but you don't know do you? I mean, if I was
in prison or really bad (ill) or something..."

"I don't know... I can see it... but... I can see
it but I'd probably... I don't know... Do you think
you'd ever be self injurious?"

"Yes, I can empathise with A.... he's blind, he gets
frustrated ...

INTERVIEWER: Can you envisage engaging in self
injurious behaviour yourself?

Yes.... no.... it depends, doesn't it? I don't think I

would but ... why do you think A. bangs his head,
then?"

In the home for people with sensory disabilities, a high degree of empathy was expressed for the supposed frustration clients must feel due to their lack of sight and/or hearing. When framed as a cause for the self injury, nurses could empathise with the behaviour.

"If I shut my eyes and I couldn't talk, it would
just boil up... if I wanted a cup of tea and you
couldn't understand, I'd be in a real rage..."

SYMPATHY

As chapter two revealed, while empathy is a concept valued in nursing, sympathy is viewed as inappropriate and unhelpful in the client/care relationship. However, as defined in the literature, it is an emotion which is felt by many of the research participants. Sadness was also mentioned in reflecting upon the self injurious behaviour :

"I do actually find most of them (challenging behaviours)
very sad, anyway.... because most of them are related to
attention. But I think self injury is .. far more..
upsetting ... to see someone doing that..."

"I find it really, really sad.. because self injury is
the ultimate behaviour ... it's more difficult
than any thing else..."

When returned to in the second round of interviews, two of the carers said that feeling sympathy for the self injurious individual was a useful emotional stance in many ways :

"I find if I'm feeling sorry for someone who's head-banging, and being... difficult... I don't get, get carried away in it... and I can be more in control..."

"It (sympathy) keeps you feeling... you don't get you don't shut off like you can..."

Closely allied to these emotions were those of pity expressed for individuals who engage in this behaviour.

"(Referring to the noise an individual makes while self injuring) It makes me feel sad... it makes me feel really sad sort of pitiful..."

Some of the participants, when asked to explain/explore these feelings equated self injurious behaviour to physical disability or illness, as something the person 'couldn't help'. (See 'fatalism' below).

"It's not his fault he can't see, is it? And it's not his fault he bangs his head..."

"She can't seem to not do it..."

BEHAVIOURAL RESPONSES

The second section in this chapter concerns the behaviours which the carers identified as correlates to their emotions. This was the easiest of the three to follow up on in the second

round of interviews as behaviour may be more easily identified and named than the concepts discussed in the other sections. Also, with one or two exceptions, the research participants were more comfortable talking about their behaviour than about their beliefs or emotions, perhaps as a space could be made between the 'self' and a behaviour, which it is difficult to make between the 'self' and an emotion. Humour played a larger part here, too, with the research participants laughing at and about their own (and my) behaviour, both past and present. A small proportion of this was rather black humour, so common in the caring professions, but most of it was genuine amusements at the contortions one engages in to maintain an appearance of coping. Fewer themes are presented in this section than in the other two as this material was easier to code : the behaviours described by the research participants fell quite easily into the five themes presented below.

CRYING

A common reaction to initial contact seems to be crying, as a result of shock or distress at witnessing self injurious behaviour.

"Didn't want to go back. I went home, right,
cried buckets that night. I hated it..."

"She just got the other arm and just kept
punching and punching her face and I was
just crying..."

Most of the nurses who reported crying at first contact with self injurious people did this when they were at home, rather than in the care situation. This changed when carers 'settled into' their work situation, but at first, this reaction was one which was very private. The one noticeable

gender difference was the women interviewed were quite open about this reaction, and very often it was one of the first reactions mentioned in the first round interviews. Some of the men also mentioned this spontaneously, but a few appeared to need 'permission' to admit to this behaviour, commonly:

"INTERVIEWER: Some people have said that
they were very upset by the behaviour and
cried when they first saw it..."

The reason for crying, at this stage, appeared to be the shock of seeing someone purposely hurt themselves and, in some cases, the ferocity and, in others, the evident long-term nature of the behaviour.

"When I first saw J.'s hands, I wondered where
she got her scars and cuts from... I couldn't...
believe it, Maggie, when I saw her.. picking.."

"The first time C. started, I ran out of the room..
went to find a qualified... I was.. terrified..."

Many of the carers talked about feeling tearful for much of their first weeks or months at work, but actually crying at home. One nurse (above) who cried when first (and subsequently) in contact with self injurious people, felt that she was perceived as,

"... no use at all... someone would have to come
and take over from me..."

With increasing familiarity with the workplace and with colleagues, a few of the interviewees said they felt they could cry when upset by an incident of self injurious behaviour, but this was far more common if one were physically hurt by an aggressive person.

The length of time that crying as a response lasted varied from just once, to over three months. Some participants reported still (after some years of experience) feeling tearful on witnessing incidents of self injury :

"Yes, it's still like that sometimes...."

One of the research participants differentiated this crying in herself between :

"Crying because I'm sorry for her and
(crying) because I'm angry with her and
with me..."

However, for the other carers who reported crying as a continuing, intermittent response, it was linked to acute outbursts in individuals or a sense of helplessness when faced with self injurious behaviour on a daily basis.

"(It) gets you down, really.... you wonder why you
bother... my husband says I should work in a bank
and then I wouldn't have anything to... you know...
it wouldn't get to me..."

AVOIDANCE

A consequence of the emotions described above was the reported tendency on the part of the nurses to avoid self injurious clients within the care situation. The context of this behaviour is important : all of the research participants are people who have chosen to work with this client group and, particularly for one of the homes in the study, particularly with people whose behaviour may be seen as challenging. Thus, in 'opting out' of working with self injurious individuals, one will be 'opting in' to working with people who display a whole range of different

behaviours - largely destructive and aggressive behaviours.

"I don't mind if J. tries to kick or punch, at least she's interacting... it's when she sits and picks..."

"S. can be a real pain when he's at you all the time, but I find that's more... I can cope with that better than P bashing himself..."

"(laughing).. the only thing I hate more than that (self injury) is when M. starts picking his bum..."

Initially, this is reflected in the expressed wish not to return to the work situation, which was commonly reported :

"It had a traumatic effect on you, you know, you think, 'What is this all about?' and I felt like jacking it all in...."

"I just walked out of there and I really didn't want to go back..."

As noted earlier, some carers did leave this client group for work perceived as less stressful. These moves were largely viewed as temporary - as a rest - with the person's identity as a carer remaining with people who may challenge. Most people who expressed this initial trauma found it difficult to pin down why they had carried on in those first few months, apart from those who were dependent upon the income and/or those who did not want to ask for a change of client

group and thus be seen as 'not coping'.

On a longer term basis, staff will manipulate their own workloads and responsibilities to avoid self injurious individuals.

"And I find myself now.. umm.. avoiding him

...because I don't know how to handle it...

INTERVIEWER : You still avoid him?

Yes, I still find myself avoiding him... which is
bad"

"I don't often choose to work with them.... I just
can't handle it....."

The research participants were very aware of trying to keep a balance between swapping 'groups' or individuals with other carers for whom self injurious behaviour did not cause such a major problem and being seen to take their share of the work with self injurious people and maintaining their own emotional equilibrium.

"If Sue and I are on, she always takes her...

I can't bear her banging and she can't bear

G. kicking... that doesn't bother me...."

"If he's on my group... and I have him for the
day, then I wish I'd rung in sick...."

"If he wanted to stay in his room for the day..

listening to his radio... I'd let him.. to keep him
out of the way...."

The summer periods over which the interviews took place highlighted this issue, as there was much discussion about who was going on holiday with whom. The prospect of a week in a caravan or cottage with a self-injurious person filled some of the carers with dread. For the registered nurses, it was not possible to avoid particular clients in this way as they always worked as the only qualified nurse. Some of them felt they had to care directly for the more 'difficult' clients and these often included the self injurious individuals. Their avoidance tended to be shorter lived :

"If she's really freaking me out, I
disappear to the loo for ten minutes...."

CHILLING OUT :

The stressful nature of caring for self injurious individuals meant that most of the carers had established patterns of winding down from work. In some cases, these strategies were conscious and the research participants could talk about how and why they were effective. Others were much less aware of the process, but when asked could identify some 'chilling out' behaviours. Physical activities were commonly used :

"After an early, I get the surf-motor out with
a few mates and rip... you can let it all go...
chill out... "

"I walk down to the station... or stomp down..
and that gets it out..."

"It's about 45 minutes drive, so I kind of review
the day and that's it... I leave it..."

INTERVIEWER : Does that always work?

Mostly. I've got the kids... and Sharon's
(interviewee's partner) always got things...
sometimes we talk work, but we do try
not to..."

Others found talking about work therapeutic:

"On a Friday night, we'll have a bottle of wine
and talk over the week... that's good..."

"We (referring to colleagues) spend hours on
the phone, particularly if it's been a bad day...
you need to... talk it out, don't you, or it...
just goes round and round...."

All of the people interviewed said that they felt that working with self injurious people spilled over onto their non-working lives, and many resented this. One team leader said she would spend her days off worrying about a client if there was a problem and only resisted ringing up as she thought the other staff would feel she did not trust them. Not being able to 'dump it' was, however, seen as part of the job.

"When I was away (interviewee had just
returned from holiday) I found myself lying by the

pool.. drink... sun.. all that... and found myself
thinking about M.... what is this? It's what you
do, isn't it?"

BELIEF SYSTEMS

The final section of the analysed data deals with the belief systems which underpin the emotions and behaviours described above. The follow up conversations over the themes which are called belief systems caused the greatest discomfort for the research participants and a few sticky moments for me. I think, in retrospect, that this was due to the laying bare and the articulation of the foundations for people's practice. I was most appreciative during this part of the conversations that I had on-going relationships with many of the interviewees and thus avoided appearing too threatening. Those who had reflected on their reactions acknowledged that the judgements they made about these other factors and the way in which these influenced their intervention was based on idiosyncratic judgements on their part and this seemed to be a cause for concern.

The contradictions and anomalies of both the value set underlying intervention and the interaction with clients had not often been examined this closely in carers and open discussion of these, which was prompted by the first round of interviews, caused discomfort. For some nurses, particularly those who had only recently been registered, the fact - appearing rapidly through conversation - that their care practice was not theory or research based was raised by

them as a point for discussion. This was undoubtedly linked to my role as a teacher:

"Aren't you finding this awful, Maggie.... all those
years in school..... and not a hint of normalisation..."

In the second round of interviews, much of this material is peppered with statements like, "I never really thought about it like that...", ".that's difficult.... I don't know..." whilst my questioning became more persistent, " why do you think it's like that?", "what makes you feel like that?"

Some nurses assumed that the framework to which they were working was common, despite rarely, if ever, articulating this to other staff. While the clients and their behaviour occupied that thoughts and conversation of the carers while at work (and often whilst not at work) the broader issues around caring for people with perceived problems was not a topic of conversations. The way carers feel about an individual or a particular behaviour, or the client group as a whole was largely treated in general conversation in a light way and the conversation I had at this stage with the research participants was a fairly novel experience for some of them. Conversations which took place between staff at handovers and care reviews tended to address particular issues in the care of an individual rather than the aims and focus of the care given. Thus, in the absence of clinical supervision, carers were not offered the opportunity to explore and share the premises for their practice. I will return to this issue in chapter six.

However, it became apparent that most of the interviewees took their own belief system as a communal 'given' and it appeared that the assumption was that everyone working at a particular home was working to the same premises. This struck me as odd, on two counts : firstly, that this assumption should exist at all, given the absence of confirmatory conversation; and, secondly, that real and fundamental differences between the belief systems of carers appeared through

conversation. As they had to struggle to formulate what could be perceived as nebulous and perhaps shifting ontological and interpersonal bases for practice, why should they assume these are common?

FATALISM

One area which emerged during the first round of interviews, which I found intriguing was that which I have described as a sense of fatalism around the self injurious behaviour. Despite being engaged in programmes designed to diminish this behaviour, many of the nurses expressed a high degree of doubt about ever successfully intervening in long - term self injury. For some nurses, this seemed to be no more than a deeply held conviction about particular individuals :

"At the end of the day, you won't stop his outbursts...

he'll always have them...."

"I think it's getting to know them and.... (accepting)

that you're never going to change it.... it'll always

be aspects of their life..."

"There'll always be something - environmental, physical,

anything, that makes her bang her head...."

When questioned further on these issues, the carers appeared to be locating the self injurious behaviour within the individual, as something that the learning disabled person is, rather than something that they do in response to a specific set of circumstances or an emotion-set. This obviously links with the theme of acceptance outlined earlier. Some nurses saw the behaviour as initially environmentally acquired but then internalised to become part of the individual's

personality.

"Perhaps E. just saw someone else doing it when she was a kid... whatever... it's just what she does now, isn't it?"

"I think A. started headbanging because of his Dad and the pressure... but his personality needs it..."

For at least two of the carers, a religious explanation was invoked, and self injurious behaviour was viewed as something which God had created the individual with, and which would always be part of them:

"That's the way God made him, Maggie, and we won't change it...."

In all of these cases the self injury was seen as a corollary to the individual's learning disability, rather than as a separate entity and whilst acknowledging that cognitively ordinary people engage in self injurious behaviour, carers cited the high numbers of people with both a learning disability and self injurious behaviour as support for this link. This theme links strongly to the next.

HELPLESSNESS

This attitude also seemed to be part of a deeply held sense of helplessness in caring for the self injurious, learning disabled person. Even nurses who design and monitor plans, and talk about them with enthusiasm then contradict these attitudes when the issue of the likelihood of these behaviours 'disappearing' is raised.

"That is the real downside of caring for people
who are self injurious ... that you wish you could
find the root cause and eradicate that and it just
never seems to be ... I don't know, myself, of any
self injurious person who has been cured..."

"I wish there was a way of dealing with him .. but
to some extent you just... have to stand back ... and
watch..."

"You'll never stop them... they'll always do it for
something..."

Whilst it was clear that the two ideas - that self injury would not stop and that one could treat/intervene - existed simultaneously, extrapolating this from the round one interviews and bringing it to the attention of the research participants was uncomfortable for everyone. I was aware that my approach could be seen as threatening and did not want to alienate the research participants. The conversations here are marked by my interspersing and prefacing questions with phrases like, "I know this is a difficult issue..." and "It sounds as though I'm pushing, but this is important..." as a means of softening the approach. I also felt rather anxious before the interviews within which this issue was to be a major feature.

Essentially, these conversations revealed that the two concepts appeared to be used by the carers at different times and in different ways, and thus the concepts rarely came into consciousness at the same moment. The first - that of intervening with individuals in the prescribed manner - was that used during everyday interaction with the individual and with other carers. It also formed part of the cluster of activities which the carers thought of as

'nursing'. The attempt to reduce self injurious (and other challenging) behaviour was something which they did as part of their job. The second concept - that of the necessary part which self injurious behaviour played in the lives of some of the client group - served, I think a different purpose, and was also used differently. These ideas of the behaviour being an immovable and irreducible part of the person linked to the carers' feeling of 'knowing' the person and of the continuity of this relationship through time and space.

"If I'm still here in twenty years, Mags, A. will
still be banging his head..."

"She's been doing that since she was a kid..
and she'll do it whoever's around..."

Most of the staff felt that following care plans and programmes around reducing the self injury was worthwhile as they felt they did produce a reduction in self injury at times. Others felt that the fluctuations in self injury with any one individual over time were 'natural':

"P.'s a lot better than he was... say five years
ago... used to be blood everywhere.... but he
still has a bit of a go..."

This was one theme over which there were noticeable differences between the nurses and care assistants. Even if expressing fatalistic views around the continuation of the behaviour, the registered nurses generally felt that care interventions were worth pursuing. One participant, a professional nurse who had been in the field for many years, felt that carers were disillusioned because there had been insufficient energy put into interventions and because of poor management of nursing activity. She was firmly convinced that self injurious behaviour could

be dramatically reduced if not stopped. She did, however, comment,

"I see it rather like smoking - cutting down is
good, and stopping is great. But it's always
there... to be ... if you need it..."

For those who felt that fluctuations in self injurious behaviour were about what was happening in the person's head and not linked to the environment, the responses to questioning about interventions were varied. Some felt that they followed the care plan because it was expected of them, but with no real faith in the amelioration of the behaviour. Others remained willing to be convinced and carried out the nursing intervention with a faint optimism :

"You have to keep trying, don't you..
you can't just abandon.. them.."

"Something might click one day..."

Managing these tensions as a means of dealing with helplessness within daily work will form the focus of the final chapter.

THE CAN'T HELP IT'

As well as placing the self injurious behaviour firmly within the individual, carers also sought variables within the self injurious person to account for their reactions to it. Thus in the first round of interviews particularly, it was difficult to shift the focus of the conversation to the participants themselves and away from individual clients. I initially perceived this as a problem

but it proved useful later as difficulties in the second round of interviews : identifying features which made a difference in reacting to self injurious behaviour between individual clients could be facilitated by using material from the first round as 'start-up' points for these conversations.

One factor which had a strong influence on the reactions of carers was the perceived ability level of the client.

"It's easier to deal with P. because he can't... he doesn't give anything back....

INTERVIEWER : So you don't find that behaviour as draining?

No, no I don't, no..."

"I mean, with C. you have to work out why she's bashing herself... but with A. he could just tell you and that's frustrating.... "

Paradoxically, it appeared that the less able the client - in terms of self-care, communication and social skills - the less emotionally difficult the behaviour, despite the responsibility issue raised below.

"I get pissed off with J. sometimes... she knows better than that... and she knows it..."

"There's a lot of things.... not banging...

M. could do if she wanted.. it makes me

mad...."

Part of this association was, I think, the feeling that the less able the self injurious person was perceived to be the more responsibility the carers felt for the behaviour. It seemed that the responsibility for the behaviour moved from the individual to the nurse on a sliding scale of ability. On questioning, the issues of responsibility and control were also linked : less able people had less control and, therefore, the nurse carried greater responsibility for the individual's well being. Given the person's limited behavioural repertoire, the nurse could teach new skills and thus had a greater feeling of 'doing' something to ameliorate the self injury.

"You feel far more responsibility toward a vulnerable
person like that..."

"You rack your brains trying to think what's causing
it... you need to find it, so you can stop it..."

Conversely, responsibility declined for the more able, an extreme example being :

"I'll find out what it's about, and if it's something
stupid, like he hasn't got his belt on tight enough
that he can't breathe, I'll think, 'Go on, then...
have a go, if that's what you want...'"

The ability to use language, appeared to have a strong influence on how carers feel about self injurious behaviour within individuals. The greater the language use a person has, the less responsibility carers feel for the behaviour, and the less understanding of and sympathy toward the behaviour is expressed. The ability to use language was equated with the ability to think through difficulties and problems and, therefore the use of self injury by the comparatively

articulate was seen as unnecessary.

"She could just tell you, couldn't she... it's like
wanting to.. make you hop..."

"When it comes to it, J.'s clever enough to ask
for some things, and all that picking just
winds people up..."

The registered nurses were also more likely to float the idea of more able people who self injure
having a mental health problem which contributes to the behaviour than they were the less able.

Interestingly, vocalisation during the self injurious act also had an impact on carers:

"I think C. is distressing because it's over long
periods of time and he also vocalises loudly
at the same time..."

"It's compounded by the fact that he makes a lot of
noise, you know... which I don't like very much.
... you know... when he bangs and hurts himself..."

It is important, in the context of the relationship between ability, responsibility and care, that it is
non-verbal vocalisation which occasions this increased concern in carers. One client, who was
discussed extensively by his carers would incorporate their words into shouting during episodes
of self injurious behaviour. This evoked a different reaction in the research participants - one
which involved both anger and fear :

"He'll just throw your words back at you..

it's not even worth trying...."

"(That's) so.... God! so irritating... when he
does that, I could kill him...."

This anger appeared to be linked to a sense of rejection of attempts to help and a feeling of helplessness in the face of this person's self injurious behaviour. Although largely unspoken, I feel that many of the carers shared the feelings about this behaviour expressed by one nurse:

"It's so spooky when he does that...
really psycho, you know?...."

The fear was expressed by many nurses that hearing their words incorporated into the act somehow validated it, and thus compounded their sense of failure.

As seen from the last quotes and those used earlier, the correlation between higher ability and increased emotional management problems persists.

EXPLAINING THE BEHAVIOUR

Whether the carer could see a cause for the behaviour or not also influenced his/her reaction to it, although often these causal links were worked out on an ad hoc basis. This issue was followed up in the second round of interviews in some detail, and it seemed that for less able clients, some carers would run through a sort of checklist to try to discover the cause of the self injury:

"I see if she's hungry or thirsty or bored or got
some pain or whatever... and if I can't work it

out it really worries me ... I'll lie awake at
night thinking..."

Within this seeking for explanations for self injurious behaviour, some reasons were seen as 'good' and others as 'no reason at all'. Pain was seen as the 'best' reason for self injury.

"C. gets a lot of pre-menstrual stuff.. pain...
that causes her scratching... I can understand
that..."

"I sometimes think he must have a ... headache or
something... or earache... to do that..."

More able people were expected to have other ways of dealing with pain. Other 'good' reasons included being frustrated with oneself or others and "not being able to tell you" about needs or wants. 'Bad reasons' were: being selfish; attention seeking; and being bored. When carers evaluated a reason negatively, they found the behaviour more difficult to deal with emotionally, even if they recognised the validity of it.

"It would be better if she had her days
filled up... but, well, just head banging
because you're not going anywhere... it's
stupid...."

The idiosyncratic nature of these evaluations was evident to the carers throughout the interviews, and one area which caused some embarrassment was that whether a carers liked a particular person or not influenced their evaluation of the reason for the behaviour. For example, in comparing two self injurious people one nurse commented:

"I have great respect for P, I really do like
him... and I never... I'm not being unfair to
A... but I never thought that P.'s was ...
bad behaviour..."

Another said:

"I can't take to C..... he winds me up something
chronic... I've told him how I feel...."

And, of a different self injurious client:

"Yes... I love B....I'm his keyworker..."

Conversely, as we saw in the section on avoidance, the fact that a person is self injurious can colour the whole relationship to the point where the client is shunned.

"J. just turns my stomach.... I just have to tell her to
go away... I cannot just sit there and watch her...
I have to tell her to go away..."

For a few of the carers, the statement of liking particular individuals and not liking others required no qualification. However, in the majority of cases, this fact seemed to cause embarrassment and was prefaced with expressions like, "I know you're not supposed to have favourites," and "I do treat them all the same, but...". This may reflect the ethos of the uninvolved practitioner to whom patients were just patients, or the basis of the current care system in utilitarianism.

The final factor which seemed to influence carer's emotional reactions to self injurious behaviour was that of the assumed intention behind the self injurious act. Nurses reported

feeling quite differently about clients who "can't help it" than they do for those "who know exactly what (they're) doing". The whole concept of the purpose of the behaviour, which some staff differentiated from the cause quite clearly, was a strong factor in deciding upon appropriate intervention. Obviously, these ideas are related to those discussed earlier around ability level as those who were perceived as not blameworthy were invariably the less able. However, even amongst this group, some individuals' behaviour was seen as having a distinct purpose, which was evaluated by the carer. The separation of cause and purpose occasioned much hesitation for some of the research participants, but they felt that individuals could have what was perceived as a 'good' cause for the behaviour, yet engage in it for other purposes. An example of this, and of the least acceptable purpose, may help to illustrate this point :

"I know D. does get bored, but he's banging, like
now, to get your attention..."

The woman mentioned earlier with pre-menstrual pain and resultant self injury was viewed sympathetically by most of her carers. However, one felt that :

"All that scratching... yes... it's... she has pain-
killers and everything... I think it's all to attract
attention...."

In some instances the cause and purpose were seen as congruent, for example, the frustration behaviour mentioned earlier, but these were not a majority.

Thus, it seemed that nurses felt most irritation with those clients for whom the perceived intention was to gain attention through self injury, whereas those who gained the most empathy or sympathy were those who were thought to have few alternative behaviours.

"Well, A. gets himself all hyped up for it, you

can see... and if he wants to do it, he will....."

"Sometimes he's touching it (the injured cheek)

like this, as if to say, 'What have I done?'... he

knows he's doing it, you know, Maggie... he

knows... so what can you do?"

"Well, he can't do anything else, can he? I can't see

any way of stopping him hitting his ear..."

For the less able, carers felt that their intervention was warranted and that they were helping in some way, even if only by physically restraining the self injurious person:

"You just have to hold her hands till she... till

she's calmer..."

If some element of manipulation is involved - self injury as a way of attaining something - then carers felt angry and resentful towards the individual:

"INTERVIEWER: How do you feel about that '

'lead up' to the behaviour?

Umm.. she's taking the pee, isn't she? If she can't

get her breakfast first, or no-one's taking her out...

she'll have a go... talking about it like this... it's

sad... but at the time, you're sort of... caught..."

"It's the same ones who don't play up who don't

get anything. I mean, C.'s got her own house

and her own staff and that's all through being...
challenging... I really get annoyed, because you
can see what's happening...."

"I let him do it... that sounds terrible, doesn't
it, but... you know... he'll just jerk you around
all day...."

When asked how judgements about intention are made, carers felt that knowing the individual was the essential key to responding appropriately. Research participants found this difficult to articulate:

"Well, you know, Maggie... you just know,
don't you?"

When pushed:

"It's getting familiar with their habits and ways..."

"You can see it's about knowing people when
we get your students here... they have a heyday
them... some of them listen... but some of them
have to learn the hard way..."

Conversations with the interviewees took place away from the people they care for and so afforded an opportunity for direct reflection on practice. The carers frequently commented upon how, in quieter moments they 'felt bad' about some of the emotions engendered in the care

situation, and in conversation, as above, used phrases like, "I know this sounds awful," and, "I'm not really this bad, but...". Often, at these times the professional back ground which I share with the participants was appealed to, with interviewees saying, "You've been there..." and "You know what it's like..". And indeed I do.

AMBIVALENCE

The last chapter of the work is an interpretation of the analysed data presented above. One of the themes which underpins it was present in all of the codes identified above : that of ambivalence. The conversations held with the research participants were marked by hesitation and by ambivalence about what they wanted to say and about how to say it. The emotions, beliefs and behaviours feature contradictory and opposing ideas - not wanting to come to work/ loving one's work, understanding/not understanding self injurious behaviour - and this ambivalence can be physically seen in the transcribed data, as in the excerpts above and below. Conversation is littered with pauses and fillers (umm..., hmm..) are used extensively. Nurses often answered questions or requests for clarification about their emotional responses with "I don't know.." and needed much time and space to work through their thoughts and feelings.

"I don't know... umm.. this is really hard, isn't it?..."

I mean, I'm not..."

"Probably.... no... maybe...."

" (long pause) Do you know, that's a very good point..."

(long pause) I'm more.... umm... I'm trying to think

of the word...."

I would suggest that much of this indecision is representative of the struggle carers have not only to articulate their emotions and beliefs but also to hold together conflicting emotions and belief sets within the care framework. It is the ambivalence which marks this struggle which led to the naming of the thesis as carers so clearly wrestled with and wavered over these factors which make up the emotional labour they undertake.

As the work progressed and my confidence and skill in the interview situation increased, I was able to leave silences in the conversations more comfortably, and prompts became less directive. Given the space for clarification of feeling and for the formulation of responses, the research participants often looked hugely relieved at having managed to articulate a particular idea.

"...talking about it like this... it's sad... but at the
time, you're sort of... caught... yes, that's it....
you're trapped in the situation with her..."

"... I'm just not cutting it, I'm not coping. You
know, that's been in my mind for a while, but...
I've never said it..."

Clashes between what the research participants thought they ought to be feeling and doing and what they actually did feel and do caused some ambivalence in the way in which they saw themselves :

"I like this work most of the time... but it's hard

to keep your... wanting to do the best for them..

when they're winding you up..."

"Personally, he is, although he's challenging in other

ways... Umm... but he is... it's awful, isn't it?...oh, God,

what a terrible nurse...."

It was interesting that, on taking the research findings back to the participants, many expressed relief that their feelings were shared by others and that their ambivalence about their work and their emotional reactions to self injurious clients were not unique. The final chapter of the work takes this ambivalence as its base from which to explore the research findings, and frames this as central to understanding caring within this field.

CHAPTER SIX

THE IMPORTANCE OF AMBIVALENCE

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THE IMPORTANCE OF AMBIVALENCE

This final chapter presents an explanation of how carers work with people with learning disabilities who engage in self injurious behaviour. It represents an interpretation of the analysed data from the last chapter and is presented in a fashion which lends itself to use in practice. It is suggested in the chapter that the concepts of care reviewed in chapter three may not fully address the long term care situation and that a dynamic, intra-psycho conceptualisation is needed. The chapter also pulls together themes which have been appearing through the work as echoes in both the methodology and in the evolution of the theory. The resultant framework will be contextualised in the light of professional and care issues which formed foci in the earlier work.

It is important to remind oneself at this point of the work the research participants do - caring for people with learning disabilities who engage in self injurious behaviour. For many of the carers, self-injury, often severe self injury is witnessed on a daily basis. Many of them are called upon to physically intervene to prevent another person from banging their heads on the walls and furniture, from beating their faces with their fists and from biting their hands and arms. Whilst this intervention is in itself traumatic for carers it occurs within a work context of this (and other challenging behaviours) being imminent, even whilst one is recovering from an incident of violence. The emotional intensity of such work is reflected in the research participants' extreme reports of their feelings about individual clients (love/ hate) and in their expectation of a limited career span with emotionally demanding individuals. Also reflecting this intensity are the patterns of opposing emotion and belief they describe which formed the major themes in the analysed data. I would suggest that the ambivalence which is the title of

both the thesis and of this chapter reflects the struggle which individual carers have in continuing to hold together and hold apart conflicting emotions and beliefs within the framework of caring.

HOLDING APART/HOLDING TOGETHER

In Menzies' (1960) original study, an exploration of the rate of loss of student nurses, she suggested that the caring role evoked three conflicts for nurses. The first of these is emotional attachment v. detachment and the second, also closely linked to the high levels of guilt which Menzies uncovered, was that of a situation in which nurses were apparently given responsibility, but in fact, the care system within which they worked reduced their autonomy and, therefore, their ability to take responsibility. Another conflict, and one which is important for this piece of research, was that between personal defence systems and the social defence systems within the organisation. In order to continue to care for patients, Menzies suggests, nurses employ defences used first in infancy : denial; projection; identification and splitting. That nurses employ regressive defensive behaviours is an idea supported by Holden (1990) whose findings are reminiscent of those of Menzies.

Two of the concepts raised by Menzies - guilt within the care situation and the clash of personal and organisational defence systems - resonate within the current work. This work may be seen as an extension of Menzies' work within the particular realm of caring for people with learning disabilities who self injure. The attention within the original work to intra-psychic processes and mechanisms has been largely overlooked by the profession in the intervening years but provide the interpretive framework for this piece of research. Doubtless, many factors have contributed to the profession's failure to fully address Menzies' work : in relation to this research

the relationship between this type of explanatory framework and the interpretation of dominant ideologies in practice will be revisited. Whilst the ideology which underpins care practice locally - Social Role Valorisation - acknowledges the unconscious forces in play within the care situation, indeed, issues around death and destruction, the discussion will focus on the received practice of the theory, which emphasises the social aspects of the work.

The nurses in the study are having to deal, on a day to day basis, with acutely conflicting ideas, beliefs and feelings. These stem from a range of sources, both intrinsic and extrinsic to the care setting itself, but have to be mediated and either resolved or 'held' by each nurse - an intra psychic process. The theory proposed here is that, because such conflicts are essentially irreconcilable, the nurse becomes caught up in having to 'hold' them. I will elaborate below on what this holding process may mean, but first will indicate the kinds of conflicts involved and their sources.

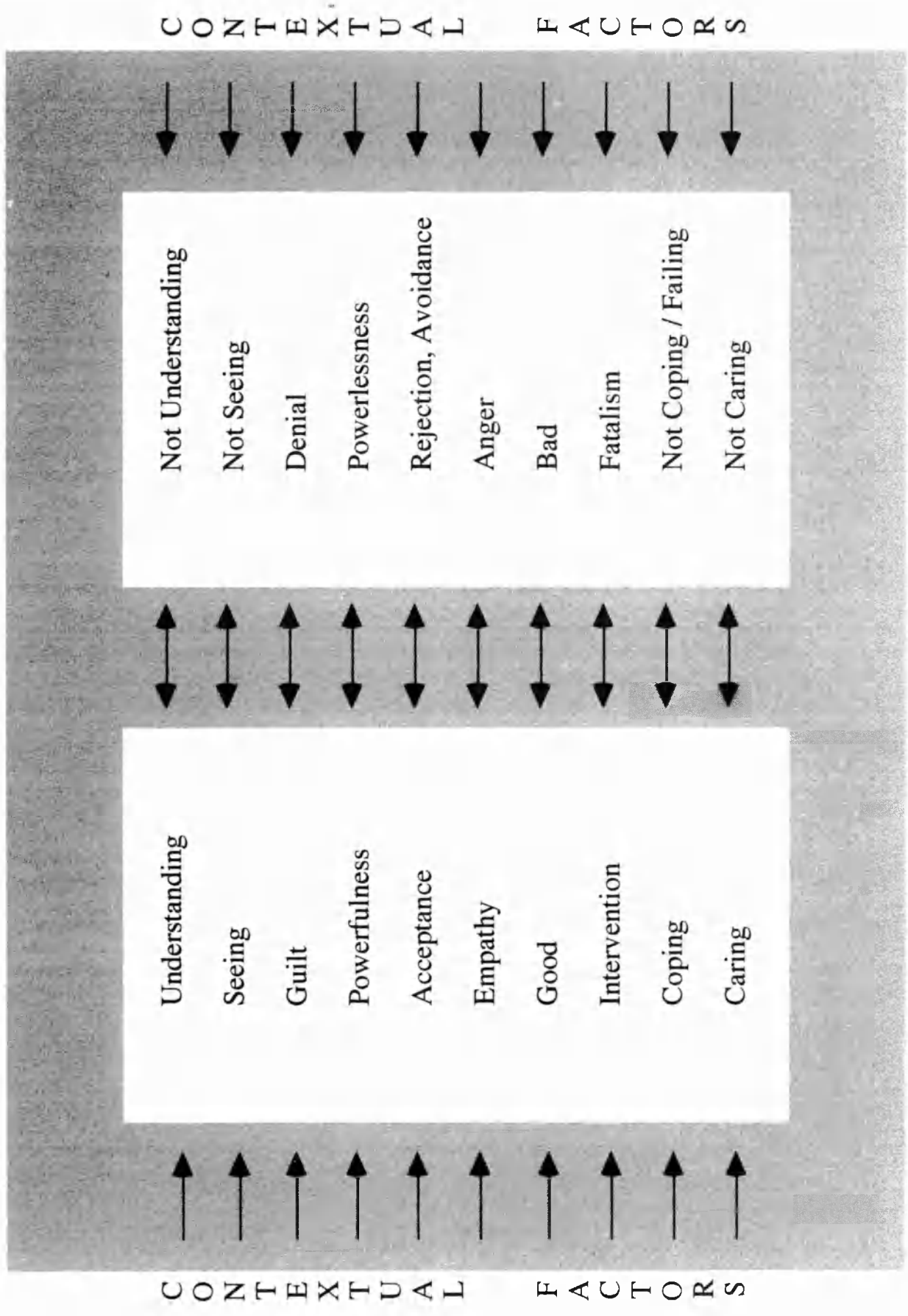
As the previous chapters have shown, nurses are beset with explanatory frameworks, theories and ideologies, both about their caring role and about the nature and appropriate management of people who self injure. These offer conflicting and contradictory messages. The setting in which they work sets another kind of context and framework for their role, with expectations about how they should behave, present themselves, relate to other staff and, indeed, feel about the people for whom they care. Again, there are inherent contradictions and conflicts. For example, the pressure to be involved, but at the same time, detached and calm; to provide a social and sociable living environment but at the same time to contain and control - therapeutically and safely - behaviour which is far from socially acceptable or conducive to quality of life for those individuals or their peers and carers. Such messages are internalised by

nurses as a part of their professional socialisation, leading them to a situation where they are carrying a range of conflicting and contradictory beliefs and emotions within themselves.

The holding process, which I suggest nurses are engaged in as a result, involves pressures in two directions : pressure to hold these conflicting, contradictory beliefs and emotions together, that is, they cannot easily reject them; and pressure to hold them apart to prevent, in a sense, some kind of psychic implosion as massive contradictions become exposed to internal view. I suggest that holding together and apart these conflicting ideas and feelings constitutes complex and difficult emotional work on a care environment already fraught with trauma. I would further suggest that it is the holding together and apart of these polarities which makes it possible for nurses to continue to care. This intra psychic environment is portrayed on p. 192. The polarities indicated are drawn from the data, presented in chapter five, and are discussed in the next section of the chapter.

When focused upon within the research interviews the conflicting nature of the emotions and belief systems reported caused embarrassment and difficulty to the participants. Each of the research participants held opposing sets of beliefs and experienced conflicting emotions and thus, as in Menzies' work, I am proposing an intra - psychic explanatory framework. This discomfort may suggest that at the level of day - to - day work these opposing thoughts and feelings are kept apart in order to facilitate the care process. In this case, the obvious dis-ease felt and expressed by the research participants would illustrate that this holding is, in fact, one way in which carers defend themselves against the destruction and disease so clearly symbolised and enacted around them.

The Intra Psychic Care Environment



The characterisation of clients into good/bad, blameworthy/innocent etc. and of the self into good and bad may serve as a protection against the anxiety generated within this situation : it may relieve carers of the need to engage with complex processes of analysis and evaluation within an already tense and changing emotional environment and presenting a challenge to this splitting mechanism occasioned anxiety and defensive reactions in some of the research participants. This splitting may also act as a means of enabling caring relationships to be maintained with others who evoke such disparate and disturbing emotions. Thus I am suggesting that 'holding apart and holding together' constitutes a defence mechanism which enables carers to continue to work with this client group - an intra psychic explanatory framework.

Craib (1989) discusses defences which may be too rigid and thus unwieldy and, perhaps, damaging. Some of the carers in the study appeared to be more flexible in their approach to caring for people with very challenging behaviour than others. These carers seemed able to form a more realistic picture of the client, the care situation and their role within it. These nurses were more able to bear the exposure, through questioning, of the conflicts involved in the care situation and to discuss these. They were able to form more integrated images of the self and the other within the care situation - a point returned to later in the chapter - and consequently to bring into play more sophisticated models of the self within care. They were more likely to engage in 'what if..' conversation and to bring alternative strategies for care into the discussion. They appeared more aware of the effects that they as individuals might have on the clients' and their behaviour and of the vagaries of 'life with others' which make caring a dynamic process. I suspect, although the data presented for this current work cannot substantiate this, that as a consequence, these nurses provide more client- centred and appropriate care.

For other carers this mechanism of holding apart leads to unrealistic pictures and expectations of : the nurses themselves; the clients; the work the nurses undertake. If these carers interact with the clients on the basis of the somewhat rigid categories described in the previous chapter (good, irritating etc.) they may not see or appreciate change and growth in individuals. Similarly, if, as proposed, the holding together and holding apart of these emotions and belief systems constitute the individuals' defences then loosening these to allow for change in the position of either the carer or client may be perceived as dangerous. The defences are there to obviate the kind of work which the loosening of these boundaries would necessitate. Consequently, I would suggest that these mechanisms may prevent the carer from developing alternative views of their work and themselves and thus from developing defence mechanisms and processes which might facilitate more realistic pictures of the work and more flexible and individualised care.

The diagram on p. 192 of the intra - psychic care environment, illustrates the opposing sets of emotions and beliefs which the nurses are holding both together and apart in order to continue to care. The outer sets of arrows in the diagram represent the forces which shape the carer's view of him / herself : his/her role; the work which he/she undertakes; the relationships within this. These may vary according to circumstance - the factors which would shape the self of individuals caring for their own children would be very different from those shaping the self for paid carers. However, I feel that in this instance, the issues around professional history which were discussed in chapter three will be important, as will the professional and historical frameworks explored in relation to care for this client group, which were explored in chapter two. The physical environment will also have an impact on how the carer perceives him/herself : a grim living/ working environment delivers clear messages about worth and value. Relationships which the individual carer has with others in the immediate and wider staff group

involved in the same work may also form part of this process.

I suggest that in order to continue to care for people with learning disabilities who engage in self injurious behaviour, individual carers need to hold these forces in a continuing balance with the conflicting emotion and belief sets generated by their relationships with learning disabled people. This process is dynamic, the carer engaged in a largely unconscious struggle to maintain safe distance between the conflicting emotions and belief sets and yet to retain the integrity of the emotional aspects of care. The interpretation offers the view that for the individual, allowing these polarised ideas to come together is too difficult : yet the very interaction with self injurious individuals within the broader context creates and charges these conflicting emotion and belief sets.

Whilst for purposes of clarity, a number of the research participants are represented in the extracts in chapter five, I am proposing that this struggle to maintain emotional equilibrium is a challenge for each individual. Conflicting emotions and beliefs were expressed by all the carers : ambivalence was experienced by each. In order to illustrate this process, the following section of the chapter explores specific examples from the text.

UNDERSTANDING / NOT UNDERSTANDING

The first of these - understanding and not understanding - perhaps underpins all the others. Throughout the interviews, research participants would present explanations of self injurious behaviour on a general and specific level, indicating some kind of understanding of the behaviour. Carers suggested many reasons why people may engage in self injury : for attention - "You know, I'm just going to hit myself really, really, hard because I can't get attention any

other way..." (p. 139); as an attempt to "wind up" the carers - "I really feel as though M's getting on my case..." (p. 144); as a frustration response, "I can empathise with A... he's blind... he gets frustrated..." (p. 159); or as a response to unmet physical need - "C. gets a lot of pre-menstrual stuff... pain.. that causes her scratching.." (p. 180). However, at the same time they also claim not to understand: "If I knew why he did it.. it would be.. more understandable..." (p. 147); the material on p. 159 reflects this ambivalence over understanding when carers were pushed, during the second round of interviews, on this issue. Nurses also reported worrying about not understanding: "...if I can't work it out, it really worries me..." (p. 179/180).

SEEING /NOT SEEING

The set of ideas above is closely linked to that of seeing and not seeing the self injurious behaviour. Carers talked about getting used to the behaviour (pp. 154 - 157) and ordinarily not seeing it. They also talk about the shock of "re-seeing" the behaviour. Staff could see the self injury and its effects - "people stare, don't they, when she's got plasters and that all over her hands and up her arms.." (p. 149) and yet the reality of the behaviour was not perceived: "it just wasn't so bad after a while..." (p. 156). Avoidance was also used as a means of not seeing the behaviour. Despite having chosen to work with this client group - and therefore, to see this and other emotionally difficult behaviours - carers expressed the desire and the need to avoid them. Many talked about not coming back. Sometimes this was a response to their first contact with people who self injure - "I just walked out of there and I really didn't want to go back.." (p. 165). For others, this was an on going reaction to their work with this client group: "If Sue and I are on, she always takes her..." (p. 166). For some, it was envisaging a limited working life in this care situation. Thus carers could both see and not see the behaviour in many different senses.

GUILT / DENIAL

Another conflicting set of emotions and beliefs which were mentioned independently but which also ran through the interview material generally was that of guilt and denial. Carrying guilt and responsibility for the behaviour was very difficult for the research participants and defence by denial enabled them to gain some sense of control over the care situation. This is achieved through a denial of the world in which the client lives, which is manifested in many forms. As the data showed carers make their own assumptions about the meaning of the self injurious behaviour, and, indeed, about the learning disabled person's world. Szivos' work (1992) is some of the later literature which emphasised the importance of understanding how a person with a learning disability perceives his/her world and him/herself within it. Much of this literature makes painful reading. Attempting to understand the learning disabled person's perspective - particularly the multiply disabled person - calls for enormous feats of imagination, tenacity and courage. How much simpler and less painful to create a world for them and thus the assumed world which each carer creates for the cared-for serves to deny the real world of the learning disabled person. The world which the individual research participants created was assumed to be shared by others, which was an assumption not supported by the evidence raised in the research (see the discussion on p. 170). Distancing oneself from the client, as illustrated by the denial of the pain felt as a result of self injurious behaviour (p. 150/ 151) represents another form of denying the learning disabled person's qualities and, consequently, presents the opportunity to reshape that person and their world. An example of this is the carer who thought that either he or the clients changed as the behaviour, "wasn't so bad after a while..." (p. 156).

Echoes of the denial of both the impact and the importance of the behaviour can be seen in other themes from the last chapter and also in the language used by the research participants. Engaging in self injurious behaviour was frequently referred to as, "having a go", the

nonspecificity of which serves to reduce the impact of that described. The acceptance of the behaviour as 'just the way she is', also serves to reduce the horror of the act and enables carers to continue to work with the client group. Examples of this are : "... not until a good three or four months did I begin to accept it... Accept it as part of the job.." (p. 157); and, touchingly, "Love him, love his ear - bashing.." (p. 157).

Carers also, as in Menzies' (1960) and Holden's (1990) work, felt guilty about the occurrence of the behaviour and the part they may play in its appearance or maintenance. The last chapter presented this guilt in two guises : that around direct causality and responsibility for the behaviour and in being part of a care system which caused and perpetuated the behaviour. As the section on 'fatalism and intervention' shows, the nurses in the study spend a great deal of their time involved in care strategies to reduce self injurious behaviour in individuals and, once a self injurious incident has begun, they feel that they should be able to 'do something' to stop it. Thus carers have an image of themselves as powerful, which is addressed below. Craib (1989) suggests that guilt is a condition of life and must be borne, despite our need for reparation. Hinshelwood (1994) raises the concept of altruism in this context : that altruistic behaviour is a manifestation of our need for reparation, which is dependent upon our knowledge of pain and guilt. Craib (1989) also addresses this issue raising the very pertinent question of whose needs are being met within the caring relationship. If the attempts at reparation, Craib suggests, seek to restore without the experience of guilt this type of relationship requires a dependent 'other'. Many practices within nursing generally are open to the criticism of fostering dependence in others, and the maintenance of adults with learning disabilities within the child role has long been a focus for attack within the specialist professions (See Wolfensberger, 1983). The guilt expressed by the research participants ranged around the part played by services and carers in

the promotion and maintenance of self injurious behaviour - "...if only I had thought of something else, perhaps it might have been averted..." (p. 137) ; "The system we work in made them like that... I feel guilty about that.." (p. 139). Attempting to bring these two sets of ideas together caused much difficulty for the research participants and for me and I feel that this is connected with issues of power and control which constitute this next set of conflicting feelings.

POWERFULNESS / POWERLESSNESS

This image carers have of themselves as powerful is partly reality : the carers in the study have an enormous level of control over the lives of the people for whom they care. Simple matters - when to get up, how to spend time, where to sit - can be and often are, decided by nurses. Awareness of this power imbalance is being raised on two fronts within nursing. The growing literature on empowerment within services generally is becoming a focus within consumer - oriented health care systems and secondly, ideas from the user movement within mental health services are beginning to filter into the disability world. These changes notwithstanding, in the daily care situation, nurses do command a frightening level of control over those in their care. This 'powerful' image is, I would suggest in relation to self injurious behaviour, also partly fantasy. Underlying their approach was the idea that they, in some way, held the key to beginning and ending self injurious behaviour in individuals : "... you think, 'My God, is it me?' " (p. 137). If a client had been self injurious, carers would think over the situation continuously, reiterating the events in the search for the 'key' : "...something might click one day..." (p. 175). For particular incidents of self injury, carers would try to find 'the' cause or the 'right thing to say' and the client who would use carers' words as part of his self injurious episodes, appeared to have touched upon this by disavowing the power of their words in his action.

However, these same nurses see themselves as powerless, as unable to prevent or influence the course of self injurious behaviour (see below). This was reflected in the nurses' fatalistic attitude towards self injury, which was at odds with their care-intervention behaviour. Powerlessness was also reflected through the panic and anxiety occasioned by the behaviour where nurses felt that they had to act, but did not know what to do : "All I can do is hold his hand..." (p. 140). Powerlessness, as Craib (1989) suggests, was also shown in their fear, which itself sprang from many causes. Carers were afraid of : being physically hurt - "You feel you may be the next target" (p.146); of not knowing (p.147); of the harm individuals would do to themselves and how this might reflect on the carers - "Look at all those boxers... they've got brains like mashed potato because of it.." (p. 150) ; of failing the client in some way - "It's nice to hand over he's been good..." (p. 151). Thus the research participants perceived themselves as vulnerable - personally , professionally and emotionally - as well as perceiving themselves as powerful.

ANGER/EMPATHY

The research participants seemed less uncomfortable exploring conflicts revealed in the interviews and data analysis relating to emotions than in discussing those relating to belief systems. Those titled 'Anger / Empathy' on the diagram subsume a grouping of pity, sadness, sympathy on the one hand and anger, hostility and irritation on the other. Carers' expressions of anger tended to be linked to perceived attempts by the learning disabled people to manipulate them and their emotions : "I get pissed off with J. sometimes.. she knows better than that. ..and she knows it..." (p. 176) ; "He'll just jerk you around all day... " (p. 184). However, anger was also felt as a response to the carers' inability to prevent or stop the behaviour : "and then I get mad because I didn't see it coming... I couldn't think.... how to... stop it..." (p.144); "I get so

ratty with them when they won't stop..." (p. 144). At the same time carers expressed sympathy, empathy and sadness for the self injurious person : "it (sympathy) keeps you feeling ... you don't get shut off... " (p. 161); "I find it really sad, because self injury is the ultimate behaviour..." (p. 160); "My God, the way P. crashes his head... he must be desperate to hurt himself like that..." (p. 150/151). The participants related feeling sympathy for and feeling sadness about the clients they liked, and very rarely for those they disliked. In a parallel fashion, carers were more likely to feel or at least, to express, anger with the clients they disliked than those they liked. Whilst more able to discuss emotions than underlying value/belief systems the attempts made during the interviews to raise conflicting feelings about a particular individual as a topic for conversation and to hold them together proved difficult.

ACCEPTANCE/REJECTION

As touched upon above, the research participants were very accepting of some people with learning disabilities who self injure (and of the behaviour itself) and rejected others with the same needs and difficulties. Acceptance and rejection may also be seen as another set of feelings and attitudes which need to be kept apart. The carers frequently expressed warm and accepting feelings toward some self injurious individuals ("I love B...") and rejected others. The basis for acceptance or rejection appeared to lie in the amount of 'blame' carers felt individuals warranted for engaging in the behaviour. Although the variables presented in the previous chapter stand - those of history, of perceived ability , of language use and of the immediate precursors of an incident of self injurious behaviour - these seemed to be applied to different individuals by nurses in different ways. The material in the previous section on how self injurious behaviour was used to 'wind up' carers is evidence of rejection of the individual's needs : "Then M. starts banging her head because she thinks, ' E. will come and sit next to me then...' and I think, ' Come

off it..." (p. 142); "J. just turns my stomach.. I have to tell her to go away.." (p. 181). However, of one person who engages in self injury : "I love B., I'm his keyworker.." (p. 181); and "It's not his fault.." (p. 161). When the issues above, which seem to enter into discussions around 'blameworthiness' were pursued in the second round of interviews, research participants became very uncomfortable and these were not easy conversations. The same was true of the next set of ideas : of good and bad clients and good and bad carers.

GOOD/BAD

The 'bad' clients were those who were not perceived as having a 'good' reason for their self injurious behaviour - winding up the staff being a very bad reason. Those people who were perceived as 'blameless' were, therefore, labelled 'good' : "It's not his fault he can't see is it? And it's not his fault he bangs his head" (p. 161). These judgements, once made about an individual, were held fast. Exploring more closely the basis for the judgement or embarking on more detailed conversation around feelings for a particular individual invariably aroused anxiety on the part of the research participants. This need to label and contain is, I think, an example of the difficulties the nurses have with experiencing and exploring complex emotional reactions within an extraordinarily emotionally challenging situation. It seems that the way in which carers are able to continue to work is by labelling clients and any attempt to form a more realistic picture of the individual than the stereotype is too difficult. Further, many of them found it almost impossible to identify likeable features in someone labelled as 'bad' or, indeed, anything to dislike in those the carer had labelled 'good'. Both Menzies' (1960) and Holden's (1990) work identifies this splitting of patients as a way of containing anxiety. This unrealistic picture of the individual client may have detrimental effects on the care he/ she receives and the evolution of a more balanced view of individual clients would seem to be one way in which care received

might be improved. To a lesser extent, nurses also judged themselves as good or bad, often describing themselves and their behaviour at the time of a self injurious incident as bad : "... it makes me so mad. And I feel bad about that too...." (p. 144); "Oh, God, what a terrible nurse..." (p. 187) As the previous chapter noted bringing together these sets of conflicting ideas caused obvious discomfort with an increase in requests for affirmation of worth from me.

FATALISM/INTERVENTION

The ideas which are titled 'Fatalism' and 'Intervention' touch on belief systems which form the foundations of the individual's nursing practice. Nurses expressed contradictory views about the nature and tractability of self injurious behaviour and, therefore, their role in caring for this client group. Fatalistic opinions were expressed quite freely in conversation : "You're never going to change it..." (p. 171); "...it doesn't matter what you do or who you are.." (p. 142). Yet these were contrasted with conversation around intervention : "well, you know what you have to do... it's all in the care plan..." (p. 131). Holding apart these two sets of ideas was, is, I think crucial to continuing to care. Seeing this behaviour as somehow out of their hands - ("That's the way God made him, Maggie, " (p. 172) - serves to relieve some of the feelings of guilt and responsibility and yet the carers feel the need to 'do' something : "You have to keep trying, don't you.... you can't just... abandon.. them." (p. 175).

COPING/NOT COPING

The last two sets of ideas to be addressed here draw into the heart of the research : coping / not coping and caring/ not caring. The carers in the study often seemed to perceive themselves as failing in the care of self injurious individuals : "It's a sort of failure when you haven't had a shift where A. hasn't had a go..." (p. 151). The long term nature of the behaviour also presented as a

failure, as successive interventions failed to ameliorate the behaviour. The research participants reported not coping in a variety of circumstances : on initial contact with self injurious people - "You're no good at it, C. you're really not coping with this..." (p.153); in relation to limits and boundaries in their everyday work - "sometimes you just have to say to someone else, 'Can you do this?'...it's the thought you can't cope..." (p. 153); in terms of their 'career' with the client group being fairly short term (see p. 154). And yet carers had opted to and continued to work with self injurious people and so their very presence attested to their coping and caring (see below) at some level. The sets of feeling discussed above, and, I would suggest, the dynamic processes of holding these both together and apart enabled nurses to continue to cope and to care.

CARING/NOT CARING

I would suggest that the interview material demonstrates that nurses do care for the people with whom they work. They expressed strong positive feelings for individuals - "I love B..." (p. 181); "I've got great respect for P..." (p. 181) - and worried about them - "I lie awake at night thinking..." (p. 180); "I found myself by the pool .. drink... sun.. all that and I found myself thinking about M ." (p. 169). They were concerned that they were becoming hardened to the impact of self injurious behaviour - "It's the wrong thing to get used to..." (p. 156) - and whether this would damage the care they gave. Yet at the same time nurses saw themselves as not caring. They gave concrete examples of being 'bad' nurses : "It does frighten me that one day he'll have a heart attack and probably he will one day... but that's only selfish on my part because I don't want him to have a heart attack when I'm on his group." (p. 150) ; "Well, I just think, 'Go on, then, you're going to do this, whatever I do.." (p. 177). However, at the same time they express the feeling that they do not want to change jobs and that they do, in fact, care. Those

carers who had spent time looking after people with learning disabilities and additional needs other than challenging behaviour saw these periods as a 'rest' and had come back to caring for this particularly needy group.

Thus, for each carer I suggest it is the holding together and apart of these emotion and belief sets which constitutes his/ her ability to continue to care.

CARING IN NURSING : DISABILITY AND DENIAL

The literature review in chapter three on caring in nursing left some questions about the applicability of that material to the longer term care situation. This literature represented care as something which is difficult to pin down, but essentially unproblematic per se. The work which specifically addresses emotion in care is unclear about what should constitute the focus of concern and operates at the level of conscious engagement. Menzies' (1960) original work, discussed earlier has not been fully addressed by the profession and the research undertaken here would seem to suggest that individual practitioners and organisations need to acknowledge and to facilitate access to the more complex reactions nurses have within the care situation. The research participants here, working with a challenging client group in long term care may form an epitome of this need, but to ignore the personal emotional forces within the care situation may be placing at risk both clients and carers.

In the 1970s, Moores and Grant began some work which explored how nurses for people with learning disabilities, in this case, residential care staff, felt about their clients and their jobs. It is interesting that the first of these (1977) pieces of work identifies three themes in nurses' feelings of alienation : optimism and pessimism for the clients; intolerance; and, of particular interest to

us, involvement. Another paper from the same data identified level of education as an important factor in attitude formation toward the client group and another explored patterns of interaction between carers and clients. This work is important as it began to explore issues in carers' feelings about their role and themselves in relation to the learning disabled people in their care. As I will suggest below, the implementation of social policy and ideological changes since then have combined to deny the importance of the inner world of the carer and client and have thus left nurses in a vulnerable position, forming their own defences, largely unguided and unsupported.

In light of the data interpretation, it might prove useful to briefly revisit issues raised in chapter two around the dominant culture in learning disability care. The current reliance within disability services on Social Role Valorisation as the underpinning ideology presents in practice a primarily social view of the person. Although unconscious processes within the care situation are addressed within the literature, as we will see below, the translation of theory to practice robs it of its depth and sophistication. Wolfensberger (1992) suggests to us that it is our social roles which confer value upon us, from which other social benefits accrue, and, this has led to an interpretation which holds social care as focal. The Trust within which the research participants in this study work has adopted, wholesale, these concepts and O'Brien's (1981) service accomplishments for the basis of the mission statement.

The simplistic manner in which Social Role Valorisation theory has been translated into practice gives a seductively simple picture of the aetiology of challenging behaviour and of the care required by people who challenge services - the behaviour is a result of abnormal living

environments, and can be amended by a change of place of residence, occupation and carers. The provision of valued social roles will facilitate community integration, and challenging behaviours replaced by more acceptable habits. The emphasis upon 'social' care thus demands that the carer pay attention to those needs rather than to others. Interpreting self injury or aggression in a psycho-dynamic fashion throws open huge realms of need and interaction which are at best, side stepped and at worst, ignored within many Social Role Valorisation based care systems. Whilst acknowledging that learning disabled people have, as does everyone, needs for social involvement and approval, we can also acknowledge that people with disabilities are, equally, people with spiritual, psychological, emotional needs. If we can acknowledge that the people who use services have complex emotional lives and emotional needs relating to their disability and dependence which are quite extraordinary, then we begin to acknowledge the extraordinary demands we place upon carers. Utilising frameworks other than social can provide us with insights into the emotional needs of both client and nurse within the care situation and enable the provision of other means of support. However, if the recognition which Social Role Valorisation provided that learning disabled people have the same needs as everyone else, is to be left at that, then we are guilty of a huge denial on two counts.

Firstly, there is the denial of the centrality of disability to people's self awareness. The literature on disabled people's awareness of their own disability and the impact it has on them has, over the decades, illustrated that the fact of disability is crucial and at the heart of people's awareness of themselves. (See Szivos and Griffiths, 1990, Smith and Brown, 1992). To deny this, is a denial of the individual's self. The second major denial is in the pretence that caring is in any way a straightforward occupation. The dynamics of caring for any other person are complex, shifting

and variable, and rarely emotionally easy. In the employment and minimal training of unqualified carers for this damaged and damaging client group, care services are denying the human emotional interaction involved in the complexities of the care situation.

Thus the explanatory framework above, addressing the question of how nurses continue caring, raises difficulties when viewed within current care provision contexts. The atmosphere within and ethos of the care service nationally and within the local Trust very much militates against this type of approach. The overwhelming atmosphere in caring for people with disabilities is about providing valued social roles and a good home. That more complex human emotions and motivations are involved in the whole process of relationships with a dependant and sometimes difficult person is not allowed for within the tight philosophy.

However, the explanation of continued caring does appear to reflect not only the content (as witnessed in the emotion categories outlined in chapter five) but also the tone of the participants' experiences : experiences which reflect tension and ambivalence. Whilst acknowledging that this piece of research asked specifically about emotion, it is difficult to imagine a piece of work, undertaken with this care group about their work which could avoid the issue of emotion, as it is central to the labour in which they engage. Caring is a dynamic process, which involves emotional involvement on the part of all who undertake it and this work offers one way of understanding how that caring might be undertaken.

DEFENCES

What of the means described above through which the nurses defend themselves within this

difficult situation? Craib (1989) suggests that difficulties arise for individuals when defences are, "inappropriate, exaggerated or too rigid" (p.146). The defences constructed and used by the carers involved in the study seem to involve the creation of an unrealistic picture of the clients for whom they care (love/ hate) and unrealistic expectations of themselves (not being angry, tired, wound up). In absorbing the culture within which they were socialised (actually and historically) and in working within a process of problem-solving, nurses may be setting themselves unachievable images and goals and making necessary the defences outlined. If self injurious behaviour is framed as a 'problem' which the nurse is to 'solve' then s/he may well be setting both him/herself and the client up to fail. Whilst the defences outlined do appear to be effective for the carers (witness the low drop-out rate among the research participants), it is difficult to gauge the effects of these mechanisms on the clients. Menzies' work highlighted the damage done to the patient group by the defences employed in institutions, and some of the mechanisms employed here may be similarly detrimental. Holding apart conflicting feelings may make it difficult, if not impossible, for carers to see both the positive and negative sides to individual clients, which is stultifying in terms of relationship development. Similarly, holding apart feelings of (for example) powerfulness and powerlessness may prevent the carer from forming a realistic picture of the possibilities within the care situation. Craib (1989) also makes the point that the world we construct in order to defend ourselves is very brittle and serves as an easily shattered defence. A recognition of the potentially damaging nature of the work undertaken by these carers entails an acknowledgement that some defences may be necessary. However, in order to enable carers to work optimally and to provide appropriate care, support mechanisms other than those currently available would seem to be needed in order to generate flexible and realistic defences.

Before the future of the work is discussed, I would like to draw some parallels between the emotional defences established and maintained by the carers in the study and a Kleinian account of defences early in life. The atmosphere within which the research participants work is filled with destruction, indeed, self destruction, and the centrality of the death instinct in Klein's work (Hinshelwood, 1994) has obvious resonance here. The client group's self injurious behaviour represents a powerful and constant reminder of the urge to self destruction which Klein would suggest is present in all of us and it is this behaviour to which the research participants address their professional efforts. Klein also emphasises how this destructive impulse may be directed toward others (Rycroft, 1985) and the behaviour of many of the clients for whom the research participants care includes (in some cases) quite high levels of aggression toward others as well as the self.

Elliott (1994) suggests that many of the defences used by the infant are aimed at limiting anxiety: these defences include projection, introjection and splitting. Julia Segal (1992) explores the possibility that these defences may also be used throughout life and Craib (1989) proposes that the learning and growth in these early stages of infancy are repeated throughout adulthood. The echoes of these defences in the work described are clear : carers find it necessary to hold apart the good and bad in their environment and also in themselves. In seeing the client as wholly good or bad, carers are resolving conflicts of emotion by seeing others as part objects. Finally, we may note an echo of the move in infancy to the depressive position in carers who can bear the ambivalence of acknowledging a mixture of emotions for some individuals and around their own situation. "What the baby learns at this stage .. is something we all have to continue doing for the rest of our lives : coping with ambivalent feelings : the closeness of love and hate" (Craib, 1989, p. 149).

The last ten years in nursing has witnessed the rise of the question, "Who cares for the carers?", as a recognition of the stressful and often difficult work undertaken by nurses. Radsma (1994) suggests that nurses often find it difficult to support each other and to care for themselves and questions, consequently, their ability to support and care for clients. One issue which has not been addressed, but which has been raised in the nursing literature is that, "the very characteristics which attract persons to helping professions," (Williams, 1989, p. 175) may make them vulnerable and this web of complexities around motivation to care, need for care and 'fitness for purpose' is one which the profession will have to address as practice becomes more community based and practitioners become more autonomous.

The availability of supervision and guidance appears repeatedly in the literature as a panacea to answer this 'carer' question. (Anstrom et al., 1991, Gould, 1990). Forrest (1989) reports from her work with nurses that teamwork and supervision are factors in how well one is able to care for patients and clients, as well as the opportunity to share experiences with other nurses. In Hall's (1990) article, one researcher (Aveline, 1986) described the difficulty of getting health care staff to express their feelings about their work, which did not prove to be a problem for the research undertaken here. Undoubtedly, clinical supervision, whichever model is adopted, provides opportunities for reflection, hopefully, around oneself as practitioner, in the care situation. However, as this research has demonstrated, it is the quality and type of interaction which makes it beneficial or otherwise (Butterworth and Faugier, 1992). The imposition of a clinical supervision structure, which emphasises regularity and frequency of supervision rather than quality, is reminiscent of counting the number of community contacts a person with disabilities has, rather than judging their meaning and purpose. Further, consideration needs to be given to that which is considered clinical in supervision (Hawkins and Shohet, 1993). I

would suggest that relationship between client and carer - the heart of nursing - and the nurse's response to this are central. Thus, the supervisor is no longer merely expected to facilitate reflection on action, but also on needs, motivations, which may not be readily accessible to the carer. Again, we move away from a clinical exchange with a supervisor, to a much more complex and shifting pattern of exploration.

Barker et al. (1995) also obliquely address the question of caring for the carers in their general criticism of the study of the nature of care by nurses. They suggest that if nurses are in need of care themselves then caring for the client, "may be conditional upon certain nurse needs being met" (p. 389). Framing the nurse/client relationship as a purely 'clinical' one, uncluttered by nurses' needs, desires or anxieties is a seductive - and, as we have considered, politically correct- idea of how the nursing service might work. It is, however, a unidimensional view of the people who are those carers and the total environment - physical, psychological, emotional, social and spiritual - within which they work. It ignores the more complex scenario of a tangle of demand and defence which this work would support.

This piece of research has begun to explore how carers manage the emotional labour they undertake each day. It is hoped that when implemented, the results of the study will enable carers to articulate their needs within the care dynamic, to encourage service providers to acknowledge these needs and to provide support mechanisms to meet them. The work was begun and finishes in concern for people with learning disabilities who engage in self injurious behaviour and their carers and in the hope that we can begin to recognise and meet the emotional needs of all involved in this caring relationship.

TAKING THE WORK FORWARD

This work has fairly clear implications for service providers, which are mentioned above. However, many other questions are raised by the research, which I have grouped into three areas. Firstly, at a methodological level, the whole question of appropriate research tools for the conceptual understanding and practice of care is raised. Whichever tool is used the exploration of this field will be, of necessity, slow and painstaking. The sheer length of time taken in gathering sensitive data, working with and analysing it, is costly in many ways. Oakley's (1986) original comments on interviewing women need to be considered in this context. Listening to and collecting stories - the narrative as research - may prove to be an acceptable and participant-respectful means of researching delicate issues in care (See Van Maanen, 1988).

Secondly, areas for further work open on all fronts as a response to this piece of research, and I will limit my comments in the first instance to the care of people with learning disabilities. The dynamic identified here as the means to continue to care may be specific to caring for this particular client group - to those whose behaviour presents such a direct challenge to our own emotional integrity. In caring for client groups with different needs, people with physical and learning disabilities for instance, does the framework of the necessary tension around conflicting emotions and beliefs stand? A useful step forward with this work would be to apply the theory generated to nurses who care for other client groups in order to assess its utility. Whilst speculating that the defence mechanisms employed may be the same, the emotions and belief sets which are held apart may differ according to a wide range of variables: the aim of care; projected futures etc. The participant group for this research was made up of carers from two rather different working environments. Throughout the piece the context of care has not been framed as an important influence on the care dynamic, and the changes in one of the homes

may support this. As chapter four highlighted, some substantial changes to the environment and working practices were made to the residential unit within the hospital, which, for a short period did have an effect on the way in which the carers perceived the issues within the care frame. However, this effect was short-lived, and problematic issues (some new as well as the familiar ones) emerged. Thus, the work suggests that although the issues in the care framework may affect the individual carer's view of him/herself, the mechanism will not change.

Remaining with people who self injure, a whole arena of comparison and contrast could be opened by asking the same questions of people who care for family members with the same behaviour. As a result of this comparison light may be shed on the nature of professional caring. The part played in emotional responses to self injurious behaviour by the nature of the emotional attachment between the carer and the disabled person would provide another focus of illumination. The work available within the field (Pahl and Quine, 1984, Carr, 1990, Hubert, 1991) tends to focus on more generic needs and effects of having a person with learning disability in the family, rather than asking specific questions relating to emotional responses related to self injurious behaviour. This huge area of emotional attachment within families and, specifically, between primary carer and dependent other adds much to the complexity of considering the self injurious person and his/ her carers. Whilst the literature on the concept of care in nursing did not prove particularly edifying, professional relationships are more accessible to scrutiny and, perhaps, comprehension than that of a mother or father with child may be. Whilst having acknowledged the problems for the research process in attempting to illuminate something as changing and complex as the care situation between paid carer and the recipient of that care, the nature of the parent/child relationship is by definition qualitatively different and more intense, thus rendering it even more inaccessible to the researcher.

More broadly, the final set of questions which indicate the need for further work involves taking forward the findings from this piece of work, together with that of other psychodynamic researchers into the nature of care. The arguments outlined previously and below around the political issues notwithstanding, having acknowledged the carer's emotional investment in the work and having given appropriate guidance and support in this emotional labour, how are we to judge the efficacy of this intervention? Current approaches to managing staff would suggest a numerical response - number of days of sickness or absenteeism, or whether observable aspects of work reach a pre-set standard. However, in acknowledging the complexities inherent in the care situation, I would suggest that more process-oriented, longitudinal approaches would be more appropriate and would enable reflection on the nature and purpose of care for the individual nurse and assist him/her identifying and resolving difficulties within it. These processes of supervision could themselves form the focus of research and review.

Looking Back, Looking Forward

Evaluating the theory is a matter of concern to both reader and writer. Given the theory evolved some difficulties may arise here and the reader is again referred to chapter four where the arguments outlined on the issues around the nature of knowledge will serve to suggest the questions which need to be asked here. One of the first is around the issue of credibility : is the use to which the data is put and the 'fit' between data and interpretation believable? Chapter four considered the problems in attempting to use standardised evaluation tools in grounded theory approaches to the generation of knowledge and the same difficulties apply here. It might be useful to revisit Hammersley's (1992) suggestion that it is the adequacy of the data which

supports a framework through which one may judge its validity, this data being the content of chapter five. Secondly, one may search for a coherence and congruity through the work as a whole, and the extent to which the model chosen is resonant with the epistemological mood of the piece. This research has been a process of drawing ideas from the individual participants and from the data. Similarly, the interpretative framework has emerged from the data, as it constitutes a reflection of the research participants' revealed and perceived world. And finally, transferability is an issue, which must depend on the similarity of findings under similar conditions and in similar contexts, as discussed in the section of this chapter above.

"The aims of revelation and disclosure take precedence over explanation and prediction" (Van Maanen et al., 1982, p.16). The theory which is presented springs from the analysed data, as a result of exploring and refining themes and patterns from the research participants' experiences. It aims to illuminate the processes of caring and the means by which nurses continue to engage in very difficult caring work. This recognises and echoes the way in which the research world is created by the participants and the researcher (Schwandt, 1994, p. 128) whilst reflecting the point made by Kleinman and Copp (1993) that the interpretation of data necessarily belongs more to the researcher than to the participants. Echoing the concerns raised in chapter four, there comes a point at which the researcher necessarily reviews and represents the data from an interpretative standpoint which may be removed from the participants' view of themselves and their world. The feelings incurred by this are discussed in the earlier chapter but it feels that this owning of the theoretical model is the point at which the individual researcher's contribution becomes valuable. Thus it is the tone and emotional quality of the work undertaken as well as the data described which leads to the interpretive framework. The part played by the researcher in the creation of the research world has been acknowledged and valued throughout the text and

is obviously central in the emergence of theory. Schwandt's (1994) conclusion is that knowledge is, "created, not discovered by mind" (p. 125).

An acknowledgement of this enables new means of exploring our own and others' worlds. The move away from emphases on 'scientific' criteria in research - objectivity, the reporting of 'reality' - facilitates knowing in new and exciting ways. With the acknowledgement of narrative as knowing and sensitive means of analysis and interpretation, work in the disability field can move forward to the generation of models and theories which bring together the worlds of people with learning disabilities and those of his/her in order to provide understanding. The loosening of epistemological boundaries - but not of academic rigour - opens up this possibility of knowing the realities of disability and of care in sympathetic and harmonious ways.

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